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Declaration

This research dossier has not been previously submitted in any form to this University or to any other institute of learning for the intention of assessment, publication or additional purpose (unless otherwise indicated). With the exception of acknowledgments and references presented in this portfolio, I confirm that the contents of this work is a product of my own efforts and nobody else, excluding the expected input from my research supervisors Dr Darren Chadwick and Dr Josephine Chen-Wilson.

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Date: 12.06.2018

Research

Dossier

Predicting the Well-Being of Families with a Child with

Down Syndrome

Abstract

This research aimed to identify the factors that predict the well-being of parents/carers of children with Down syndrome. It was hoped that this would increase the understanding around what factors impact the well-being of such families and also influence future interventions and supports that may be available for these families.

In total, 100 participants took part in this survey study that measured the impact of psycho-social factors, individual differences in carers, deprivation and the support needs of the child. Data was analysed using regression analysis to explore relationships between carer well-being and the listed factors.

The analysis revealed that resilience was the strongest predictor of carer well-being, suggesting that higher resilience levels results in higher well-being. In addition, being a male carer, with a younger child with Down syndrome who has lower levels of behaviours that challenge is predictive of better well-being.

Although not all factors were found to be significant overall, this study does highlight the importance of psycho-social factors and individual differences in the carer and child in relation to well-being. Finally, the findings suggest that the impact of deprivation and carer hardship on well-being could be an area of further research.

Contents

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Chapter 1: Introduction

This thesis explores the factors that predict the well-being in families of children with Down syndrome, with particular prominence on psycho-social factors, individual differences and deprivation of parents/carers. I have always had an interest in the field of intellectual disabilities. However my interest in Down syndrome stems from having a younger sibling with the condition. This has significantly contributed towards my curiosity in not only individuals with Down syndrome, but also their families and the factors which impact the well-being of these families.

Down syndrome is a genetic condition known as trisomy, where an individual inherits an extra copy of one chromosome, which is caused by an error in cell division. It is unknown as to why this abnormality occurs, however it is one of the most common intellectual disabilities. Intellectual disability is characterised by significant limitations both in intellectual functioning, such as, reasoning, learning and problem solving and also in adaptive behaviour which consists of a range of everyday social and practical skills. The term 'intellectual disability' is the most recently used term in academic terminology, therefore, this term is used throughout this thesis as opposed to 'learning disability'. Although the term 'learning disability' is still used in practice within the United Kingdom, this can have a different meaning within the United State of America for example, hence a shared language cross-culturally aids understanding and sharing of academic work.

Cognitive development within children with Down syndrome is fairly variable and usually results in individuals obtaining unique health difficulties and distinctive physical characteristics. There is no cure for Down syndrome; however the treatment available for any associated health issues and the support for learning difficulties allows those with the syndrome to lead fairly ordinary and semi-independent lives. A variety of research has been conducted over several years focusing mostly on children with Down syndrome and their families, particularly as families are predominately the main carers of these children.

Cunningham (1996) concluded from his longitudinal studies into the effects of having a child with Down syndrome on the family, that 65-70% of the families function exactly like the majority of families and are not 'at risk' due to the child's Down syndrome.

Folkman and Lazarus's (1985) cognitive theory of stress and coping proposes that any incident, such as having a child with a disability, will have different meanings and consequences for each person, and in particular, only the individual themselves can assess whether the effect is distressful or not. The majority of research within this area has focused particularly on the well-being of mothers; however more recently, there has been a growing interest in the conceptualisation and measurement of family quality of life (Brown, Schalock & Brown, 2009) and of family dynamics (Llewellyn et al., 2010). Well-being is described as the state of being comfortable, healthy or happy and can relate to both physical and mental well-being.

Relevance of the present study

The present study aims to enrich the existing understanding of the factors that impact well-being in families who have a child with Down syndrome. An additional focus of the research was looking at those families who are from a lower social economical background and how this may impact well-being. This research elaborates on the existing research base related to the well-being of families of children with Down syndrome through the use of a quantitative design, whilst also exploring issues surrounding the impact of social economic status on such families. This thesis has adopted a person centred approach throughout, with associated person centred language, as it is important that people are seen first as people and not seen primarily as 'disabled' or as a family with a 'disabled child'.

Structure of thesis

Chapter 2 reviews the literature relevant to the factors that impact well-being in families who have a child with Down syndrome. A critique of existing literature that has attempted to explore factors that impact well-being in families of a child with Down syndrome is

presented. The review concludes with a summary and outline the aims and rationale of the present study. Chapter 3 presents the empirical study, including the methodological section and data analysis. This chapter includes an abstract, introduction and rationale for the choice of method, a comprehensive account of the recruitment process, data collection, the analysis procedures and results. Chapter 4 summarises the findings of the study presented in this thesis. This discussion also incorporates implications from this work for counselling psychology practice, provide directions for future research and draw conclusions from the work. Chapter 5 concludes the thesis with a critical appraisal of the research process.

Chapter 2: Literature Review

Introduction

As noted in chapter 1, the focus of this thesis is on the well-being of caregivers of people with Down syndrome, a group of individuals who have intellectual disabilities and often require lifelong care from paid or family caregivers. This chapter provides additional information about this group and their caregivers. The purpose of this review is to explore the factors that affect well-being for families of children with Down syndrome. In order to do this, the first part of the review offers some background and provide the context for the discussion of well-being amongst these families. The author begins with a brief overview of the relevant definitions in study.

An account and critique of existing literature that has attempted to explore well-being amongst families of children with Down syndrome is then presented. The review concludes with a summary and outline of the aims and rationale of the present study.

Search Strategy

Electronic databases were searched for the retrieval of relevant articles with the following search terms used: ‘Down syndrome’, ‘Well-being’, ‘Low Social Economic Status’, ‘Coping Factors’ and ‘families with Down syndrome child’. In addition, due to variations in the spelling of some of these terminologies and possible abbreviations, the following search terms were also used: ‘wellbeing’, ‘downs’ and ‘DS’. These terms were used to search in the following electronic research databases: PsychARTICLES, PsychINFO, ScienceDirect and Psychology and Behavioural Sciences Collection. Internet search engines including Google Scholar were also used to source literature.

To make the corpus of literature more manageable to review within the time frame of the course, many of these terms were merged to narrow the results as general search terms such as ‘families with Down syndrome child’ were resulting in over 100,000 articles. Once the search terms were grouped together as appropriate, the searches were resulting in

between 30-50,000 papers however the most relevant were primarily shown first. Articles that were found were screened for their relevance and date of publication with preferences for papers within the last ten to fifteen years and papers that highlighted the definition and origins of concepts considered most salient to the research, i.e. coping. Relevant literature from the reference lists of those identified articles were also followed up. Articles were browsed initially by reading through their abstracts to consider their quality and relevance. The papers which have been included within this thesis were chosen due to their relevance to variables investigated within this study and date of publication.

As the thesis progressed and evolved, further searches were conducted to explore articles relating resilience, optimism and personality traits in families of children with Down syndrome. The search terms used were 'Resilience in families with Down syndrome child', 'Optimism in families with Down syndrome child' and 'Personality traits in families with Down syndrome child'.

Well-Being

Research into well-being has been developed over the last 50 years. An early attempt to define well-being was Bradburn's (1969) classic research on psychological wellbeing. His work marked a move away from the diagnosis of psychiatric cases to the study of psychological reactions of ordinary people in their daily lives (Dodge et al., 2012). Bradburns research specified that "an individual will be high in psychological well-being in the degree to which he has an excess of positive over negative affect and will be low in well-being in the degree to which negative affect predominates over positive" (Bradburn, 1969, p. 9). Although some researchers criticised Bradburn's work for not defining the basic structure of psychological well-being, an emphasis on positive and negative affect has been central to the work of Diener and Suh (1997). They believed that "subjective well-being consists of three interrelated components: life satisfaction, pleasant affect, and unpleasant affect. Affect refers to pleasant and unpleasant moods and emotions, whereas life satisfaction refers to a cognitive sense of satisfaction with life" (Diener & Suh, 1997, p. 200).

Felce (1997) argued that quality of life is a multidimensional construct which is determined by three key elements: life conditions, subjective well-being and personal values/aspirations. He explained that subjective well-being refers to personal satisfaction with life conditions or lifestyle. He later concluded that quality of life is defined as an overall general well-being that comprises objective descriptors and subjective evaluations of physical, material, social, productive, emotional and civic well-being all weighted by a personal set of values.

Furthermore, Schalock (2004) stated that the term 'quality of life' refers to a set of factors composing personal well-being. The factors he highlights include those mentioned by Felce (1997) as well as additional factors such as: family, services and supports, recreation/leisure and personal development.

More recent research by Shah and Marks (2004) stated, "Well-being is more than just happiness. As well as feeling satisfied and happy, well-being means developing as a person, being fulfilled, and making a contribution to the community" (2004, p. 2). Well-being has been predominately measured using self-report measures in previous literature. Werner (2013) used the Personal Well-Being Index (International Wellbeing Group, 2006) to explore well-being among family caregivers of individuals with developmental and intellectual disabilities.

Intellectual Disability

Clinically, the American Association on Intellectual and Developmental Disabilities (AAIDD) define intellectual disability as a disability characterised by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behaviour, which covers a range of everyday social and practical skills. Constructivists define intellectual disability as a socially constructed term which is both historically and culturally bound. People are labelled as intellectually disabled because they differ from a culturally defined idea of 'normal' or 'typical' intellectual functioning (Manion & Bersani, 1987). It has been estimated that 1-2% of the world's population have intellectual disabilities; with higher

prevalence rates reported among children and adolescents and in lower income countries (Maulik et al., 2011).

This disability originates before the age of 18 and is very common; most of us have friends and relatives who face such difficulties within their families. According to Psychiatry-UK (2017), about 2% of the UK population (1.4 million) have some degree of an intellectual disability . Approximately 1.2 million people have a mild to moderate intellectual disability, and around 200,000 have a severe or profound intellectual disability. Individuals with intellectual disabilities are a very heterogeneous group of people. Thus, formally recognised intellectual disability covers a vast range from people having very mild degrees of impairment who live independently to those individuals whose disability is so profound that they need almost constant support in every aspect of their life.

Children with Intellectual Disability and their Carers

Children with intellectual disability are predominantly cared for by their parents who, alongside other family members, assist as their most constant and life-long caregivers. They play a critical role in shaping the development and life experiences of their children with intellectual and/or developmental disability. In many contexts, family involvement extends over the life span of parents, with siblings and extended family members taking on caring roles, especially when parents are no longer able to (Batshaw, 2005).

Families supporting children with intellectual disabilities may in some cultures differ from families who do not have a child with a disability. These differences may include increased risk of exposure to socio-economic disadvantage (Emerson et al, 2006); exposure to disability-related discrimination; coping with exceptional and prolonged caring tasks; complex interactions with disability services; and continuing to provide support into later childhood, adolescence and adulthood (Blatcher et al., 2005). Many of these differences are also shared by families supporting a child with other types of disabilities and are likely to vary as a function of social/cultural context and the nature/severity of the child's impairment.

The majority of research in this area has focused on the well-being of individual family members, especially mothers. More recently, however, there has been growing interest in the conceptualisation and measurement of family quality of life (Brown et al., 2009) and of family dynamics (Llewellyn et al., 2010).

In general, mothers of children with intellectual disabilities report greater parenting demands than parents of non-disabled children, increased stress levels and poorer physical and psychological health (Miodrag & Hodapp, 2010). It should be noted, however, that in most studies the majority of mothers of children with intellectual disabilities report normative levels of well-being (Olsson et al 2008) and also report positive aspects of parenting their child with intellectual disabilities (Blacher & Baker, 2007).

Less attention has been given to the well-being of fathers. The available evidence suggests that the association between parenting a child with intellectual disability and lower well-being is much less pronounced amongst fathers and in addition, fathers typically report lower levels of psychological distress than their spouses (Emerson et al., 2010).

Down syndrome

Definition

Down syndrome is the most common genetic condition, associated with intellectual disability, an increased risk of concomitant congenital and organic differences. Down syndrome is caused by an extra copy of genetic material on all or part of the 21st chromosome. Every cell in the body contains genes that are grouped along chromosomes in the cell's nucleus. There are normally 46 chromosomes in each cell, 23 inherited from the mother and 23 from the father. When some or all of a person's cells have an extra full, or partial, copy of chromosome 21, the result is Down syndrome. The most common form of Down syndrome is known as trisomy 21, a condition where individuals have 47 chromosomes in each cell instead of 46.

History

In 1866, the British physician Doctor John Langdon Down identified a specific group of patients whose characteristics were similar in nature. They were described as having upward slanting eyes, flattening of the back of the head and poorly controlled and fissured tongues. Some aspects of the condition were described earlier by Jean-Étienne Dominique Esquirol in 1838 and Édouard Séguin in 1844 (Evans-Martin, 2009). However, no researcher had adequately identified this group of people prior to this. Dr John Langdon Down went on to publish the book “Observations on an Ethnic Classification of Idiots”, and used the name “Mongolian” to describe these individuals because of the facial resemblances to East Asian people.

It was not until the 19th century that Down syndrome was recognised as a distinct entity when international experts, including Dr Downs grandson, suggested that the name should be changed to Down syndrome after Dr John Langdon Down himself. In 1957, the genetic cause of Down syndrome, an extra copy of chromosome 21, was discovered (Hickey et al, 2012).

Statistics

According to the National Down Syndrome Cytogenetic Register for England and Wales, in 2013 there were 1,872 diagnoses of Down syndrome, 65% of which were made prenatally. There is a small chance of having a child with Down syndrome with any pregnancy; however, the likelihood increases with the age of the mother. For example, a woman who is 20 years of age has a 1 in 1,500 chance of having a child with Down syndrome, whereas a woman who is 40 years of age has a 1 in 100 chance (NHS England, 2017).

Care Needs

Individuals with Down syndrome often have physical and intellectual disabilities and their mental abilities are typically similar to those of an eight or nine year old when they are in adulthood (Rhonda et al., 2013). They usually have poor immune functioning and typically

have an increased risk to a number of other health difficulties, including congenital heart defect, epilepsy, leukaemia, thyroid diseases, and mental disorders, among many others (Hickey et al, 2012). They also commonly reach developmental milestones at a later age.

Those with Down syndrome may have some or all of the following physical characteristics: a small chin, slanted eyes, poor muscle tone, a flat nasal bridge, a single crease of the palm, a protruding tongue due to a small mouth and a relatively large tongue (Perkins, 2009). Subsequently, these airway changes can lead to obstructive sleep apnea in around half of those with Down syndrome (Hickey et al, 2012). Other common features include a flat and wide face, a short neck, excessive joint flexibility, extra space between big toe and second toe, abnormal patterns on the fingertips and short fingers.

Most individuals with Down syndrome have a mild or moderate intellectual disability with some cases having severe difficulties (Batshaw, 2005). As they age, people with Down syndrome typically do not perform as well as their same-age peers whilst some after 30 years of age may lose their ability to speak (Patterson et al, 2013). This syndrome causes about a third of cases of intellectual disability. Many developmental milestones are delayed with the ability to crawl typically occurring around 8 months rather than 5 months and the ability to walk independently typically occurring around 21 months rather than 14 months.

Although individuals with Down syndrome may share some similarities, they will typically vary in areas such as appearance, personality and ability. Some may have more severe difficulties than others, however, this may become more apparent as the child becomes older. Many children with Down syndrome cope well at mainstream school with some extra support and many adults with Down syndrome may work and live fairly independent lives. However, most people with Down syndrome need some degree of long-term help and support, particularly as children and whilst they are growing up (Batshaw, 2005).

Role of Carers

Understandably, carers of children with Down syndrome would play a vital role in caring for their children from the very beginning and possibly even the rest of their lives. The role of these carers may be dependent on how much or how little support they have themselves from family, friends and the community around them. A carer of a child with Down syndrome would be expected to do everything required of a parent/carer of a typical child without Down syndrome (Hodapp, 2007). However, depending on the needs of the child with Down syndrome, more may be required from the carers. For example, medical support, support with personal hygiene, support feeding, additional support with reaching developmental milestones and much more.

As the child grows, it may be that more or less support is required from parents/carers however; this would largely depend on the severity of the Down syndrome. Carers may be required to continue providing every day support for their child, which may not be in conjunction with the support being provided by carers of typically developing children. Some examples may be, continued support with personal hygiene, support communicating, medical support, financial support and support to find employment.

The 'Down Syndrome Advantage'

Families of children with Down syndrome, in comparison to families of children with other disabilities, have been reported to have lower levels of divorce and greater family coping and functioning (Urbano & Hodapp, 2007). This phenomenon, known as the 'Down syndrome advantage', has been recognised relating both to the child and characteristics associated with the syndrome (Cahill & Glidden 1996; Hodapp 2007). Many studies have found that, compared to families of children with other disabilities, families of children with Down syndrome cope better (Hodapp, 2007). Families seem to be warmer and more harmonious (Mink et al., 1983), mothers experience less stress and close, harmonious relationships with

their offspring are reported by fathers (Hornby, 1996) and by adult siblings of the individual with Down syndrome versus with other disabilities (Orsmond & Seltzer, 2006).

Blacher and McIntye (2006) conducted a qualitative study exploring whether behavioural difficulties of low functioning young adults and well-being of their families varied by diagnostic syndrome. They interviewed 282 caregivers who had children with a diagnosis of either Down syndrome, Autism, Cerebral palsy or mixed Intellectual Disability. They concluded that their findings on parental adjustment supports the Down syndrome advantage with evidence that mothers of young adults with Down syndrome experience less depression and more positive impact than do mothers of young adults with other developmental disabilities (Blacher & McIntyre, 2006). Similar comparison studies have also reported that families of children with Down syndrome managed better, as demonstrated by having more cohesiveness, experiencing more reward, less stress, and less caregiving burden (Dykens et al., 2002).

Whilst research does support the Down syndrome advantage, it is nevertheless important that families of children and adults with Down syndrome are not overlooked. Although these families may seem 'better off' in comparison to families of children with other intellectual disabilities, the well-being of these families is still important and therefore should not be overlooked in the research literature, hence its consideration within this research study. The term 'the Down syndrome advantage' may be contentious in terms of its impact for families, as it may sustain stereotypes around the functioning and well-being of families who have a child with Down syndrome.

Although there may be families of a child with Down syndrome that may appear to be functioning better than families of children with other intellectual disabilities, the functioning of these families may be different when compared to families of typically developing children. Hence it is important to consider the unique needs of families of children with Down syndrome and the impact that raising a child with Down syndrome may have on the family.

Carers of Children with Down syndrome

The process of bringing up any child can at times involve stress and requires coping to accommodate and adapt to that stress (Baker et al., 2002). However, parents of children with Down syndrome are likely to encounter some challenges far more frequently than parents of typically developing children. For example, coming to terms with the child's condition and limitations, providing or finding providers for specialised care, attaining community resources, and planning for future caretaking are common demands described in survey and interview based studied with parents (Floyd et al, 1996; Chen & Tang, 1997).

When comparing families of children with Down syndrome against families of typically developing children, the Down syndrome advantage appears to disappear (Hodapp et al. 2001). Families with a child with Down syndrome report higher levels of stress, adjustment difficulties and poorer coping strategies when compared to families of children without disabilities (Sanders & Morgan 1997; Hodapp 2007). These families also report less family participation in activities, greater financial and caretaking burden, and view their children as having more negative characteristics when compared to parents of typically developing children (Rodrigue et al. 1992; Sanders & Morgan 1997).

Povee et al (2012) conducted a mixed methods study in Australia exploring the factors that predict functioning in families with a child with Down syndrome. Two hundred and twenty four primary caregivers of children with Down syndrome aged 4 to 25 years old took part. Questionnaires were completed by participants for the quantitative component of the study and for the qualitative component participants were asked for written feedback. The main finding to emerge from this study was that of 'normal' family functioning. The quantative analysis suggested that the functioning of families with a child with Down syndrome is comparable to families of typically developing children. Qualitative findings from this study also appeared to echo this outcome of normal family functioning as parents described accepting the child as part of the family and 'just getting on with it'. However, the authors

suggested that healthy family functioning could be related to the high levels of support available within Western Australia as most families reported satification with most areas of family-centred care they receive.

Povee et al. (2012) also explored the impact of having a child with Down syndrome on the family. Whilst some parents/carers reported the positive affects of having a child with Down syndrome on the family, it was reported that there were more parents/carers that felt having a child with Down syndrome impacted negatively on the family. The care demands of the child with Down syndrome, including transportation, dressing, feeding and toileting, were described as being stressful and exhausting, a financial burden and limiting the time that could be spent with other family members. Some parents/carers expressed a sense of loss for their 'own life' as the child with Down syndrome would always be dependent. Findings also suggested that the child's behavioural difficulties were associated with poor family functioning along with parental social isolation and loss of friends. There was also a strong relationship between low income and poor family functioning.

The authors of this study concluded that there is variability in the functioning of families with a child with Down syndrome. It was suggested that future research could benefit from exploring the coping strategies and environmental supports used by parents/carers as well as exploring the functioning of more disadvantaged parents/carers of children with Down syndrome.

The Role of Psycho-Social Factors in Caring for a Child with Down syndrome

Psycho-social in this context refers to the combined influence that psychological factors and the surrounding social environment has on an individual's physical and mental well-being. Individuals may not always be entirely aware of the relationship between their well-being and the environment however the two have strongly been linked within a vast number of studies.

Coping and Well-Being

Parenting a child with an intellectual disability, such as Down syndrome, may be a source of significant stress. Research findings focusing more generally on family carers of people with intellectual disabilities demonstrated that the level of parenting stress is higher in parents of preschool children with developmental difficulties than in parents of typically developing children (Baker et al 2003; Spratt et al 2007). Consequently, being able to cope with stressful situations may be paramount. Coping is usually defined as 'cognitive and behavioural efforts to manage specific external and/or internal demands, that are appraised as taxing or exceeding the resources of a person' (Lazarus & Folkman, 1984).

Hastings and Johnson (2001) found that coping has an effect on level of parenting stress, however, the relationship between parental stress and coping has not been comprehensively explained. Hastings et al (2005) found that active-avoidance coping is associated with a high level of stress and mental health difficulties in both mothers and fathers of preschool and school-aged children. Smith et al (2008) revealed that regardless of the level of child's symptomatology, the well-being of mothers of toddlers with an intellectual disability was associated with a lower level of emotion-focused coping and a higher level of problem-focused coping.

Turning to literature specifically focussing on the family carers of people with Down syndrome, Hsiao (2014) conducted a study exploring family demands, social support and family functioning in rearing children with Down syndrome. A cross sectional, correlational research design was used with a sample of 83 families (80 mothers and 75 fathers). The results from this study suggested that families with older children with Down syndrome, greater parental education, higher family income, less family demands and greater social support experienced healthier family functioning. Conclusions from this study also supports prior research suggesting that families that face fewer demands and perceive higher levels of social support function better than those that face multiple demands and perceive limited social support (Snowdon et al, 1994; Dyson, 1997). Hsiao (2014) concluded that future

research could benefit from examining sources of informal/formal support and also recognised that there is a need to include other family members in future research.

Van Der Veek et al. (2009) looked at emotional well-being in 553 parents of children with Down syndrome (aged 0-18). They used measures of goal disturbance, cognitive coping, social support, partner bonding and coping self-efficacy within their questionnaire.

Findings revealed that social support seemed primarily relevant in explaining positive affect in parents. The coping strategy 'positive reappraisal' also correlated significantly with positive affect whereas coping strategies of 'self-blame' and 'rumination' were positively related to depressive symptoms. Hence, social support and coping styles both were important in the psychological well-being of family carers of people with Down syndrome.

Nelson-Goff et al. (2016) used a mixed methods design to explore the experiences of 445 parents of children with Down syndrome over four different phases of the life span. The aim of the study was to understand changes in coping and life satisfaction in relation to well-being in parents. They concluded that parental coping strategies are significant in relation to well-being and life satisfaction however coping strategies may vary over different points of the life span. The findings from this study also indicated better coping strategies in parents of children with Down syndrome during middle stages of the life span.

They hypothesised that this finding could potentially be due to the added burden and stressors associated with caring for aging children who are often not as independent as children without disabilities (Nelson-Goff et al. 2016). As this study was carried out in the United States, the authors recommendations were for similar studies to be conducted across different populations to further understand and determine whether similar trends occur in other countries.

Alexander and Walendzik (2016) conducted a cross-sectional study with 49 parents of children with Down syndrome to explore whether preferred coping strategies explain differences in parental health. The parents completed self-administrative measures of

psychological and physical health and coping behaviour and hierarchical regression was used to analyse the results. They findings highlighted that parents who often used regenerative coping strategies experienced less anxiety and depression whereas dysfunctional coping was the best predictor for parental depression. They concluded with the recommendations that intervention programs for families of children with Down syndrome may beneficial if they address parents' reflections about their feelings and impart knowledge about long-term regenerative coping strategies.

Resilience and Well-Being

Similarly to coping, resilience may also be vital in being able to parent a child with an intellectual disability successfully. Resilience has been defined in a variety of ways, including, the ability to bounce back or recover from stress, to adapt to stressful circumstances, to not become ill despite significant adversity and to function above the norm in spite of stress or adversity (Tusaie & Dyer, 2004). Research related to families of children with Down syndrome has shifted from an emphasis on pathology to an emphasis on resilience and strength in families (Cunningham 1996; Hodapp 2007; Cuskelly et al. 2009).

Van-Riper (2007) conducted a quantitative study with 76 mothers exploring maternal perceptions of parental and family adaption in families raising a child with Down syndrome. The findings from this study highlighted that 70% of the mothers rated their family's overall functioning as either a 4 or 5 on a 5 point scale (1 = poor; 5 = excellent). They also found that the three variables family demands, family resources and family problem-solving communication were significantly associated with family adaption. Furthermore, they concluded that these results provided support for the belief that many of families of children with Down syndrome respond to 'a change of plans' with resilience. That is, they are able to ensure, survive and even thrive in the face of ongoing challenges associated with raising a child with Down syndrome, hence supporting the importance of resilience in family functioning and parental well-being.

Optimism and Well-Being

Alongside coping and resilience, optimism-pessimism is a notion that has also been researched in relation to the well-being of families with children with Down syndrome. Optimism and pessimism are generally defined as positive and negative outcome expectancies (Baker et al., 2005). Optimists are said to have a favourable outlook on life; they believe that good things rather than bad will happen to them (Olason & Roger, 2001). Substantial evidence suggests that optimism is beneficial to an individual's health.

Optimistic people, for example, are reported to have fewer illnesses and doctor visits, fewer accidents, greater physician ratings of general well-being, longer survival time following a heart attack or AIDS diagnosis, and a longer life (Peterson, 2000). Clarke & Beck (1999) have argued that at a cognitive level, chronic engagement in pessimistic thinking may lead to the development of a psychological vulnerability to experiencing negative emotions, which may in turn contribute towards symptoms of depression, anxiety, anger and panic.

Investigation of this concept within carers of people with intellectual disabilities and/or Down syndrome is limited and existing research is reviewed here. Baker et al. (2005) conducted a study survey-based exploring the well-being of 214 parents with a child with an intellectual disability in relation to behavioural difficulties of the child and parents' optimism. The results indicated that optimism had a consistently positive main effect relationship with parental well-being; higher optimism scores were consistently related to more positive scores on measures of well-being for both mothers and fathers. The study also concluded that optimism was significantly related to child behaviour problems as well as to parental well-being, however, optimism was not a significant mediator of the relationship between child behavioural difficulties and parental well-being.

Cless et al., (2017) explored hope, coping and relationship quality in mothers of children with Down syndrome using structural equation modelling with a sample of 351 mothers. Hope was defined as a generalised positive state that comes from a personal sense of agency.

The results from this study indicated that a greater degree of religious coping and internal coping were both significantly associated with more hope whereas support seeking was not related with hope. Furthermore, higher hope was significantly associated with greater relationship quality. Although this study did not explore optimism itself, it does indicate that feeling more hopeful can have a positive impact on carers of people with Down syndrome.

While there has not been complete consistency across studies explored so far, the findings have generally shown that parents with higher levels of social support, higher optimism and who use problem-focused coping strategies have been reported to have more positive family functioning and well-being. However, some critiques have questioned whether coping strategies are 'trait or state' dominated and the degree to which individual differences influence their use and effectiveness (Lazarus et al, 2006). We turn to the role of individual differences in the well-being of carers in the next section.

Individual Differences in Carers of Children with Down syndrome

It has been argued that we know little as to how individual differences such as parental role, personality and other family characteristics affect the likelihood of producing positive affect.

Glidden et al. (2006) conducted a study exploring personality, coping style and well-being of parents raising a child with an intellectual disability. A total of 97 mother–father dyads raising at least one child with an intellectual disability were participants. They described stressful situations related to their child and completed the Ways of Coping Questionnaire twice. Data was also collected with regards to personality, depression and subjective well-being. Findings from this study recognised that personality factors, particularly neuroticism, were predictive of coping strategy use. Furthermore, higher levels of the coping style positive reappraisal was associated with higher levels of well-being, whereas higher levels of the escape avoidance coping strategy was associated with lower levels of well-being. Overall, they concluded that parents of children with Intellectual disabilities use more problem

focused than emotion focused strategies and that use of strategy was associated with personality characteristics.

In addition, Glidden et al (2009) replicated the previous study and established that the relationships among personality, coping and parental outcomes, such as well-being, were consistent and stable over a six year time period. Furthermore, they highlighted that there were many similarities between mothers and fathers in the frequency of use of different coping strategies and also in the direction of influence of personality and coping strategy on parental outcome variables.

Although these studies included individual differences such as personality traits, they do not appear to have explored the direct impact of such individual differences on parental/carer well-being. As well as personality, there may also be many other individual variances which may impact a carers well-being, such as, if they are a lone carer, their age, gender and possibly even their educational background.

Deprivation in Carers of Children with Down syndrome

Beyond individual factors, societal and financial aspects of life may also play a role in carer well-being. It has been argued that research has tended to focus on the emotional burdens of having a child with an intellectual disability and less on the burdens imposed by the inadequate societal support for the time-consuming and expensive task of caring for a child with a disability (Emerson et al., 2006). Emerson et al. (2006) also found that the increased risk for poorer parental well-being could be attributed to their increased risk of exposure to poorer socio-economic circumstances. Furthermore, a study by Eisenhower and Blacher (2006) concluded that differences in socio-economic situation fully accounted for the increased risk of poor maternal well-being in their sample of Latino mothers of children with intellectual disabilities.

Olsson and Hwang (2008) conducted a study exploring the socio-economic and psychological variables as risk and protective factors for parental well-being in families of

children with intellectual disabilities. Socio-economic situation and hardship were evaluated by calculating the number of items that the parent would like to possess or participate in but could not afford. The items related to social activities and clothing and was adapted after Emerson et al. (2006). The results from this study showed that differences in economic hardship and self-rated health were the strongest predictors for well-being. Suggesting that as well as psycho-social factors and individual differences, deprivation may also have a role to play in predicting well-being in carers of children with Down syndrome.

Rationale & Aims of Present Study

The research presented above has focused predominately on the family functioning and well-being of parent/carers of children with intellectual disabilities. In particular there has been a focus on social support and coping styles, and some sparse attention towards optimism/pessimism, personality and deprivation. The purpose of the present study is to focus more specifically on the family carers of people with Down syndrome as opposed to generically focussing on intellectual disabilities as a whole. Intellectual disabilities cover a vast range of diagnoses and conditions and incorporates a large degree of heterogeneity. However, it is important to take into account the individuality of specific disabilities so as to be able to distinguish the supports necessary for different groups of people and their carers.

This appears to be a gap in the existing research in that the factors above have not been explored exclusively in families of children with Down syndrome but instead there have been various comparison studies within Intellectual Disabilities. The present research study adds to existing research by solely focusing on families which include a family member with Down syndrome and exploring previously unexplored factors in these carers.

The aim of this study then was to identify the factors which predict well-being in families with a child with Down syndrome. This incorporated adult children with Down syndrome too and was not limited to individuals under the age of 18 years old. This research investigation builds on previous research and recommendations by exploring four main areas in relation to

family well-being: psycho-social factors, individual differences, deprivation/hardship and behavioural/support needs of the child. Key factors of interest and factors which were recommended by previous literature were grouped into one of these four categories. These areas were chosen as they appeared to be the four prominent areas of exploration when looking at functioning of families of children with Down syndrome. Prior research has also found these factors to be inextricably linked with well-being in the general population. These areas also appeared highly relevant to the research population within the present climate as these are crucial aspects which can impact everyone's well-being.

The main research questions in this study are:

1. What factors predict well-being in families of children with Down syndrome?
2. Which coping styles are most significant in predicting well-being in families of children with Down syndrome?
3. Does deprivation/hardship play in role in impacting well-being of families of children with Down syndrome?

The current research aimed to enrich the existing understanding of the factors that impact well-being in families who have a child with Down syndrome which may be used to help inform future family interventions and support for this group of carers. An additional focus of the research was to do research about those families who are from a lower social economical background and how this may have an impact on their well-being.

Chapter 3: Method

Rationale of Methodology

The present study adopts a quantitative approach to explore the factors that predict well-being in carers of children with Down syndrome. Quantitative research traditionally adopts a positivist/empiricist approach to explain social phenomena. Positivist approaches take on an objective stance to research with the aim to separate subjectivity. This in turn increases reliability in replication and consequently begins to establish causality (Ercikan & Roth, 2006). Instruments such as surveys/questionnaires can be employed to achieve standardised measures for all taking part which allows objectivity to remain the main goal. Items on questionnaires therefore undergo rigorous testing to ensure they are reliable and valid measures where they can be easily applied to various social settings. Large sample sizes are pursued to search for 'laws' within populations to develop predictions of how the world works (Masue et al, 2013).

The aim of the research study was to identify factors which have an impact on well-being of disadvantaged parents of children with Down syndrome, in addition to identifying coping strategies and environmental supports that are most used. This study used the method of opportunity sampling to recruit participants from a target population who were available at the time and willing to take part.

Participants

In total, 100 participants took part in the study and completed the questionnaire. Of these 100, 68% were identified as mothers of children with Down syndrome, 31% fathers and 1% other relative, for example sibling/grandparent (see Table 1). As shown in the table below, majority of the participants were aged between 35 – 49 years old, are joint carers of their child with Down syndrome and 50% appear to be from a Caucasian background. The first inclusion criteria for participants was that they were a carer of a family member with Down syndrome, family members other than parents of the child were also included within this

research study as initially the research was looking at the well-being of families as a whole, including siblings and grandparents. Second and interlinked was the criteria that the family had to include at least one child with Down syndrome within the family who was above the age of 4 years old as it was recognised that this would be the point at which the child would start school. There was no exclusion criteria in terms of age of the child with Down syndrome.

Variable		**%**	**N**
Gender of participant (N = 100)	Male	31%	31
	Female	69%	69
Age Group (N = 100)	Under 35	31%	31
	35-49	65%	65
	50-64	4%	4
Relationship to Child (N = 100)	Mother	68%	68
	Father	31%	31
	Other	1%	1
Type of Carer (N = 100)	Lone Carer	8%	8
	Joint Carer	91%	91
Ethnicity (N = 100)	Caucasian	50%	50
	Asian	14%	14
	Black	1%	1
	Oriental	4%	4
	British/Unknown	31%	31

Table 1 – Demographic Information of Participant

(See Appendix 1 & 2 for further demographic information)

Design

A cohort design was applied and data was gathered using a survey design to allow the researcher to collect data objectively using a standardised measure. A battery of questionnaires were included in the survey and the results were statistically analysed using multiple regression. Regression analysis is a way of predicting an outcome variable from one predictor variable (simple regression) or several predictor variables (multiple regression) (Fields, 2009). The criterion variable within the study was parental well-being, and the predictor variables were family support, social support, resilience, optimism (sub-scales: optimism, pessimism), coping (sub-scales: confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem-solving, positive reappraisal), personality (sub-scales: extraversion, agreeableness, conscientiousness, emotional stability, openness to experience) and deprivation.

Materials

The survey was made up of 8 different questionnaires to measure the key variables of interest in the study. These questionnaires were selected based on measures that had been used within previous studies with similar research questions, including those with other carer groups, and on how reliable/valid they were. Additionally, shorter questionnaires were sought as the researcher did not want to overwhelm participants with a large number of questions. Amendments were made to the format, wording and scoring of some of these questionnaires to make the overall survey easier to read for participants. This need to be taken into consideration when interpreting the results. The 8 questionnaires are described below:

(See Appendix 3 for full survey including all questionnaires)

SF-8 Health Survey

The SF-8 is health-related quality of life measure used to assess the well-being of participants within this study and this measure was initially derived from a principal components analysis (Maruish and Turner-Bowker, 2009). The SF-8 contains eight items that measure aspects of physical and mental health functioning over the last four-week period and each item is rated on 1-5 or 1-6 scale. Each item represents a separate health domain and all items contribute to two summary scales: the Physical Composite Summary (PCS) measure and the Mental Component Summary (MCS) measure. There are 4 items in the physical composite and 4 items in the mental composite.

Lower scores on the SF-8 physical component indicate limitations in physical functioning, while higher scores indicate good general health. Lower scores on the SF-8 mental component indicate frequent psychological distress, while higher scores indicate frequent positive affect (Maruish and Turner-Bowker, 2009).

Ways of Coping Scale

The Ways of Coping Scale (Folkman & Lazarus, 1985) is a 66 item questionnaire containing a wide range of thoughts and acts that people use to deal with the internal and/or external demands of specific stressful encounters. This scale focuses on coping processes in a particular stressful encounter and not on coping styles or traits.

Participants are asked to think of a stressful situation/encounter they have experienced over the past 6 months involving their child with Down syndrome. They must then indicate to what extent they used each of the strategies listed on a 4-point Likert scale (0 = Not used; 3 = used a great deal).

The Ways of Coping Scale has 8 sub-scales - confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem-solving and positive reappraisal. Each sub-scale is scored by adding each of the items together.

Higher scores for each sub-scale indicate that the participant uses these coping behaviours more often than they used other behaviours.

According to Lazarus (1984), there are two types of coping, problem-focused and emotion-focused. Problem-focused coping is concerned with handling the source of stress, dealing directly with the situation. Emotion-focused coping is concerned with handling emotions associated with stressful situations, i.e. how to relieve the feeling of stress without actually having to change the situation itself.

Planful problem solving and confrontive coping are described as efforts to alter the situation and can therefore be characterised as problem-focused coping. Distancing, self-controlling, accepting responsibility and escape-avoidance are described as ways of managing a stressful situation through cognitive and emotional efforts without having to change the situation itself. These strategies are therefore characterised as predominantly emotion-focused coping. The remaining scales: seeking social support and positive reappraisal are more mixed in character and could be seen as either emotion-focused or problem-focused coping depending upon the situation (Folkman et al, 1986).

The Life Orientation Test: Revised (LOT-R)

The LOT-R (Scheier et al, 1994) is a revised version of the original LOT (Scheier & Carver, 1992). This scale is a 10-item measure of optimism versus pessimism and of the 10 items, 3 measure optimism, 3 items measure pessimism and 4 items service as fillers. Participants rate each item on a 4 point scale (1 = strongly disagree; 4 = strongly agree). Items 3, 7 and 9 are reverse scored and then all items for optimism and pessimism are totalled. Higher scores on the optimism component indicate higher levels of optimism. Higher scores on the pessimism component indicate lower levels of pessimism. This measure directly asks people whether they expect outcomes in their lives to be good or bad. It consists of a set of statements (i.e. “I'm always optimistic about my future,” “I rarely count on good things

happening to me") to which people indicate their agreement or disagreement on a multi-point scale.

Optimism and pessimism are generally broad, widespread versions of confidence and doubt; they are confidence and doubt pertaining to life, rather than to just a specific context (Scheier & Carver, 1992). Hence, optimists should tend to be confident and persistent in the face of diverse life challenges. Pessimists should be doubtful and hesitant in the same situations. Such differences in how people confront adversity have implications for success in completing goal-directed behaviour. They also have implications for the manner in which people cope with stress (Carver et al., 2010).

Ten-Item Personality Inventory (TIPI)

The TIPI (Gosling et al, 2003) is a 10-item scale which measures the big-five personality domains. Participants rate each item on a 7 point scale (1= disagree strongly; 7= agree strongly). The 5 sub-scales are extraversion, agreeableness, conscientiousness, emotional stability, openness to experience. Items 2, 4, 6 and 8 are reverse scored and then the average for each sub-scale is calculated. Higher scores for each sub-scale indicate that these personality traits are more evident for participants.

The Big-Five framework is a hierarchical model of personality traits with five broad factors, which represent personality at the broadest level of construct (Gosling, 2003). Each factor (i.e. extraversion vs. introversion) summarises several more specific facets (i.e. sociability), which, in turn, incorporate a large number of even more specific traits (i.e. talkative, outgoing). The Big-Five framework suggests that most individual differences in human personality can be classified into five broad, empirically derived domains (Gosling et al, 2003).

Family Support Scale (FSS)

The FSS (Dunst & Leet, 1986) is a measure used to identify the areas in a family's support network that need to be strengthened or accessed to better meet the family's needs. The

self-report FSS also measures family members' satisfaction with the support they receive in raising young children. The scale consists of 18 items covering various sources of support and participants rate each source on a 5-point likert scale (1 = not available; 5 = extremely helpful).

A higher score indicates that parents perceive some/all sources of support to be extremely helpful, whereas lower scores indicate dissatisfaction with sources of support or that they are not available to the family. In addition, the scale provides 2 open items for parents to assess other sources of support not included in the 18 items.

The family support scale was initially developed for families of children with developmental disabilities and is described as a promising assessment tool for measuring social support among kinship caregivers (Kondrat, 2014). Previous research on the family support scale among caregivers suggested that the assessment tool consisted of four underlying factors: Spouse/Partner's Family and Peers, Formal Professional Support, Informal Community Support, and Familial and Peer Support (Kondrat et al., 2014).

Sense of Support Scale (SSS)

The SSS (Dolbier & Steinhardt, 2010) is a measure designed to assess social support. The importance of assessing social support has been suggested by research, as it has linked high levels of social support to positive health outcomes, including increased psychological well-being (Dolbier & Steinhardt, 2010). The scale is a brief, concise tool for assessing the individual's global perceptions of the quality and quantity of his or her social support.

This scale consists of 21 items and participants are required to rate each item on a 3-point likert scale (1= not at all true; 3 = completely true).

The sense of support scale has 5 subscales - hardiness, approach-coping, avoidance-coping, perceived stress and symptoms of illness. In addition, 6 of the 21 items are reverse scored. Higher scores indicate higher sense of support.

The Brief Resilience Scale (BRS)

The brief resilience scale (Smith et al, 2008) was created to assess the ability to bounce back or recover from stress. The scale consists of 6 items in total and participants are asked to indicate the extent to which they agree with each of the 6 statements on a 5-point scale (1 = strongly disagree; 5 = strongly agree). Items 1, 3 and 5 are positively worded and items 2, 4 and 6 are negatively worded. The BRS is scored by reverse coding items 2, 4 and 6 and finding the mean of the 6 items. Higher scores indicate higher resilience.

Resilience has increasingly become a focus of research in the behavioural and medical sciences (Charney, 2004). However, resilience has been defined in a variety of ways, including the ability to bounce back or recover from stress, to adapt to stressful circumstances, to not become ill despite significant adversity, and to function above the norm in spite of stress or adversity (Tusaie & Dyer, 2004). In addition, the measures that have been developed to assess resilience have not focused on these qualities but on the factors and resources that make them possible (Ahern et al., 2006).

However, the BRS is said to be the only measure that specifically assesses resilience in its original and most basic meaning: to bounce back or recover from stress (Agnes,2005).

Hardship Measure

The Hardship measure used within this study was adapted from a national survey (Emerson et al, 2006) study looking at families of children with an intellectual disability. Socioeconomic situation and hardship were evaluated by calculating the number of items that the parent would like to possess or participate in but could not afford. Within this study participants were asked to indicate for each of the 11 items - 0 if they have this, 1 if they do not want/need this at the moment and 2 if they would like to have this but cannot afford it at the moment. All items were then reversed. Lower scores on this scale indicated higher levels of hardship whereas higher scores indicated lower levels of hardship.

Behaviours That Challenge Scale

The behaviours that challenge scale was taken from the paper 'Family voices: life in Ireland for Families of People with Intellectual Disabilities' (Chadwick et al., 2010). The scale was initially developed to explore behaviours that challenge within the study in this paper. The shortened version of this scale was used for the present study as the researcher was mindful of overwhelming the participants with too many questions within the survey.

(Please see Table 2 below for an overview of the measures used within the survey along with the Cronbach's alpha for each measure.)

Table 2 – Overview of Measures

Variable	Measure	Items	Recoding	Sub scales	Scoring	Cronbach's alpha
Well-being	SF-8	8	No	2 – Physical wellbeing 4 items and Mental wellbeing 4 items what are the subscales for each?	N/A	.878
Coping style	Ways of coping scale (Folkman and Lazarus, 1985)	66	No	8 – confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem-solving, positive reappraisal	Score each scale by totalling the items in each category	.933
Optimism	The life orientation test (LOT, Scheier et al. 1994)	10	Yes	2 – optimism and pessimism OPP – 1,4, 10 PESS – 3,7,9	Items 3, 7 and 9 are reverse scored.	.692
Personality	Ten item personality inventory (Gosling et al, 2003)	10	Yes	5 – extraversion, agreeableness, conscientiousness, emotional stability, openness to experience	Reverse score items 6, 2, 8, 4 and 10. Then calculate the average for each sub-scale	.717
Family support	Family support scale (Dunst & Leet, 1986)	18	No	0	N/A	.797
Social support	Sense of support scale (Dolbier and Steinhardt, 2010)	20	Yes	5 subscales – hardiness, approach-coping, avoidance-coping, perceived stress, symptoms of illness	6 items are reverse scored	.788
Resilience	The Brief Resilience Scale (Smith et al, 2008)	6	Yes	0	Reverse code items 1, 3 and 5 and then find the mean of the 6 items (scale was presented in reverse order)	.844
Hardship	Self-report hardship	11	No	0	N/A	.708
Behaviour	Behaviours that Challenge Scale (Chadwick et al., 2010)	11	No	0	N/A	.830

Ethical Considerations

Before conducting the study, ethical approval was sought and granted by the University of Wolverhampton Ethics Committee. In accordance with the BPS code of Ethics and Conduct (2009), the following ethical issues were addressed:

Valid Consent

Consistent with the Code of Ethics and Conduct, participants voluntarily consented to participation in the study. There was no coercion in the recruitment of participants, participants were able to decide themselves whether they want to take part or not. All participants were advised of their right to withdraw from the study at any point.

Confidentiality

All questionnaires were completed anonymously by participants and no personal identifiable information was asked for. Participants were informed that their identity would not be linked to the study in any way and that all completed questionnaires were to be stored in a locked cabinet at the research site.

Risk Management

Although it was not anticipated that participating in the study would cause any harm, participants were encouraged to contact the researcher with any concerns or queries should they arise. Participants were reminded that they could pause during completing the questionnaire or stop at any time. Furthermore, participants were debriefed about their experience in taking part and signposted to further support if needed.

Recruitment & Data Collection

Participants were recruited in person by presenting the research study and aims to two support groups for family members of a child with Down syndrome within the West Midlands. These support groups were specifically for families who have a child with Down syndrome and these groups were sourced via an Internet search. The group organisers were contacted

by email regarding the research study and the researcher was then invited to discuss this further with parents at the next group gathering. These support groups were aimed at family members/carers of a child/adult with Down syndrome however they were predominately attended by families of younger children which may have resulted in a skew in the sampling distribution. One additional group was contacted via email, however, they did not respond to the email and therefore the researcher was unable to attend.

Participants were initially given the information sheet (see Appendix 3) which provided details about the research, what is required for participation, confidentiality, anonymity and the right to withdraw. Those interested in completing the questionnaire were then given a consent form (see Appendix 3) where they were reminded of their rights and prompted to sign to confirm their participation in the research study.

Participants were then given the questionnaire to complete and then fully debriefed with information of their participation and their right to withdraw. Participants were given a debrief information sheet (see Appendix 3) to take away for future reference and this had all the relevant information included as mentioned above. In addition, they were given contact numbers for support services should they feel distressed or in need of further support as a result of completion of the questionnaire.

Findings from this research study will be shared with the support groups at a later stage as it is important that the participants are aware of how their feedback has been used and the potential impact it has had.

Data Handling & Analysis

The responses on the questionnaire were entered into SPSS 20, a statistical software package and then scored and analysed using this programme. The relevant scores were reversed for each measure and SPSS was used to compute various analyses of the data.

Chapter 3: Results

Aim of Data Analysis

The purpose of this data analysis was to explore statistically the relationship between key variables of interest and the well-being of parents/carers of children with Down syndrome. The chosen variables were based on findings from previous research as discussed in the literature review as well as areas which have not been explored in as much detail. Based on previous findings, psycho-social factors appear to be key predictors of well-being for these families. However, there has also been an emphasis on exploring further the impact of individual differences in relation to predicting well-being of parents/carers.

The socio-economic circumstances of parents/carers of children with intellectual disabilities had been highlighted as a potential risk factor for well-being. Therefore, deprivation/hardship amongst families was explored as an attempt to understand the impact this has on the well-being of families of parents/carers who primarily care for children with Down syndrome. In addition to these areas of interest, the impact of the support needs and behaviour of the child was also explored in relation to parental/carer well-being.

Plan of Data Analysis

Initially it was planned that a single regression would be conducted with all the independent variables incorporated. However, as the number of predictors were large (see Table 2) relative to the final sample size it was decided to group the variables and run a series of regression analyses. Furthermore, it would enable moderate to large effects of predictors to be identified within the regression analyses

A total of 4 regression analyses were conducted on the data. The screened variables were divided into the following groupings: psycho-social factors (i.e. family support, social support, resilience, optimism and coping), Carer individual differences (i.e. personality, carers gender, age, education and if they are a lone carer and total number of children in household),

deprivation (i.e. hardship and income) and support needs of the child with Down syndrome (i.e. child's age, severity of disability, living situation, support needs and independence).

The regression analyses were conducted in the category order above based on the importance of findings from the literature review. A final regression was then conducted which included all of the predictor variables which correlated significantly with well-being. The purpose of conducting the analyses in such a way was to identify the stronger predictors to begin with as research has shown that some variables may be weaker than others in predicting well-being. The strongest predictors of well-being and those variables which correlated significantly with well-being were then explored further within the final part of the data analysis.

Data Entry & Screening

First data were pooled and entered into SPSS for analysis. Data was then screened to check that all data had been entered accurately. Following this, the distribution and normality of the data was checked. To begin with, the frequency distributions for each variable were explored and each histogram graph was eyeballed to check for normality. The Kolmogorov-Smirnov test and Shapiro-Wilk test were then further used to test whether the distribution of the data deviates from a comparable normal distribution (see appendix 4).

For family support and social support, the distributions both appeared normal as did optimism and pessimism. Resilience along with the well-being variable appeared to have a negatively skewed distribution. Most of the coping subscales had a positively skewed distribution along with the personality subscales. Variables that were not normally distributed were not transformed before being entered in to the regression. This is as there are few consequences associated with a violation of the normality assumption as it does not contribute to bias or inefficiency in regression models (Statistics Solutions, 2013). The assumptions of the regression analysis were checked by checking the residual Q-Q plots for normal distribution and the linearity by checking the significant correlation coefficients.

Furthermore, the homoscedasticity and multi-collinearity were also checked along with a reasonable Durbin-Watson so there would be no autocorrelation (Coolican, 2014).

The forced entry method was used for each of the regression analyses whereby all predictors are forced into the model simultaneously. This model was selected as it relies on using good theoretical reasons for including the chosen predictors and some researchers believe that this method is the only appropriate method for theory testing (Studenmund & Cassidy, 1987). This method of entry was selected for this study as it allowed the researcher to control and group the variables entered based on conceptual and theoretical categorisation. Some of the predictors included in the regression were measured categorically and therefore were recoded into dichotomous dummy variables.

The Role of Psycho-Social Factors in the Well-Being of Family Carers

The thirteen predictor variables included in the psycho-social regression were family support, social support, resilience, optimism (sub-scales: optimism, pessimism) and coping (sub-scales: confrontive coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem-solving, positive reappraisal). The criterion variable was well-being.

Psycho-Social Correlational Analysis

Initial correlational analysis (Table 3) indicates that well-being was positively correlated with family support ($r = .234$, $p < .05$), social support ($r = .206$, $p < .05$), resilience ($r = .408$, $p < .05$) and the sub-scale of coping pertaining to positive reappraisal ($r = .212$, $p < .05$).

Thus indicating that higher levels of family support, social support, resilience and the coping strategy positive reappraisal equals increased well-being.

Intercorrelation Between Psycho-Social Predictors

From looking at the interpersonal relationship between the predictor variables, social support correlated significantly with family support and resilience was associated with having higher

social support. Optimism is significantly correlated with having higher social support and resilience. Having lower pessimism correlated significantly with having higher social support, resilience and optimism.

Correlations revealed that confrontive coping was used more when participants had greater family support, lower resilience, lower optimism and higher pessimism. While distancing coping was used more in situations where participants have lower social support and lower optimism. Self-controlling was used significantly more amongst those who reported having lower social support, lower optimism and higher pessimism. Seeking social support did not correlate with any variables. The escape avoidance coping style was associated with having lower social support and lower resilience. Planful problem solving was correlated with having higher family support and social support. In addition, the coping sub-scales all correlated significantly with each other.

Table 3: Psycho-Social Correlations Table

		Mean	SD	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1	Well-Being	27.68	5.77														
2	Family Support	48.21	12.43	**.234***													
3	Social Support	37.53	7.99	**.206***	**.423****												
4	Resilience	3.55	0.78	**.408****	.136	**.337****											
5	Optimism: *Optimism*	7.31	1.81	.060	.051	**.363****	**.378****										
6	Optimism: *Pessimism*	7.38	1.73	**.193***	-.052	**.198***	**.455****	**.462****									
7	Coping: *Confrontive Coping*	5.20	3.31	-.078	**.196***	-.111	**-.316****	**-.284****	**-.281****								
8	Coping: *Distancing*	5.08	2.75	.074	-.030	**-.268***	-.014	**-.197***	.002	**.267***							
9	Coping: *Self-Controlling*	7.03	3.73	-.100	-.055	**-.289****	-.151	**-.212***	**-.218***	**.595****	**.507****						
10	Coping: *Seeking Social Support*	8.46	3.23	-.010	.127	.166	.056	-.092	-.015	**.330****	**.369****	**.415****					
11	Coping: *Accepting Responsibility*	2.03	2.00	-.009	.163	**-.183***	**-.274****	**-.225***	**-.269***	**.542****	**.550****	**.600****	**.347****				
12	Coping: *Escape Avoidance*	3.82	4.31	-.119	.152	**-.261***	**-.405****	**-.378****	**-.310****	**.640****	**.300****	**.587****	**.305****	**.618****			
13	Coping: *Planful Problem Solving*	7.06	3.32	.145	**.268***	**.203***	.015	.038	-.114	**.579****	**.194***	**.464****	**.376****	**.402****	**.439****		
14	Coping: *Positive Reappraisal*	6.05	4.28*	**.212***	**.205***	.133	.067	.045	.037	**.366****	**.398****	**.463****	**.476****	**.479****	**.525****	**.657****	

Note: numbers in bold are significantly correlated $p < .05$ = * $p < .005$ = **

Wellbeing regressed onto Psycho-Social Factors

The regression analysis with well-being as the criterion variable and family support, social support, resilience, optimism, pessimism and different coping strategies as the predictor variables revealed that approximately 29% of the variance was explained in this model (R^2 = .29). The data met the assumption of independent errors (Durbin-Watson value = 2.049). However, the generalisability of this model was reduced when applying to a different population as indicated by the adjusted R^2 value (18%). The model itself showed a significant effect ($F(13,79)=2.55$, $p<.01$) with resilience (Beta = .359, $t(92) = 2.88$, $p < .05$) being the only factor to predict well-being. The regression model explains almost a third of the variance in the well-being of family carers of a child with Down syndrome. Furthermore, the model shows that higher levels of resilience in these carers predicts higher well-being.

Table 4: Psycho-Social Coefficients Table

Predictors	Standardized Coefficients Beta	*t*	Sig.
Family Support	.142	1.229	.223
Sense of Support	.001	.008	.993
Resilience	**.359**	**2.880**	**.005**
Optimism	-.217	-1.777	.079
Pessimism	.073	.607	.545
Confrontive Coping	.007	.045	.964
Distancing	.050	.373	.710
Self-Controlling	-.150	-.974	.333
Seeking Social Support	-.173	-1.461	.148
Accepting Responsibility	.094	.630	.531
Escape Avoidance	-.182	-1.076	.285
Planful Problem Solving	.094	.605	.547
Positive Reappraisal	.285	1.769	.081

Note: items in bold are significant predictors

The Role of Individual Differences in the Well-Being of Family Carers

The 15 predictor variables included in the individual differences regression were personality (sub-scales: extraversion, agreeableness, conscientiousness, emotional stability, openness to experience), participants gender, age, level of education, whether the participant is a lone carer and the overall number of children in the household. Information on the participant's age, level of education and whether the participant is a lone carer were all dichotomised variables and therefore dummy variables were created for each of these variables prior to them being entered in to the regression. The criterion variable was well-being.

Individual Differences Correlational Analysis

Initial correlational analysis (Table 5) indicates that well-being was correlated with the personality subscales extraversion (r = -.178, p < .05) and agreeableness (r = .214, p < .05), participant gender (r = -.273, p < .05), participant age of over 50 *(*r = -.237, p < .05) and participant education of postgraduate/other level (r = .174, p < .05).

This signifies that lower levels of the personality trait extraversion and more agreeableness result in higher levels of well-being. In addition, being a male, under the age of 50 years old and having a postgraduate/higher level of education also results in higher levels of well-being.

Intercorrelation between Individual Differences Predictors

From looking at the interpersonal relationship between the predictor variables, participant's gender correlated negatively with the personality sub-scale conscientiousness, indicating that males have more of this personality trait. Participants aged 35 or under were associated with having higher emotional stability whereas participants aged 35-49 were linked to having lower emotional stability and less openness to experience. Participants who left school at 16 years old or earlier were associated with having higher openness to experience whereas participants who had studied to degree level were linked to having less openness to

experience and being less extraverted. Being a lone carer was significantly associated with being female and lone carers were less likely to have studied to degree level.

Correlations revealed that the higher the overall number of children in the household, the lower participants levels of extraversion and openness to experience. In addition, the personality sub-scales all correlated significantly with each other.

Table 5: Individual Differences Correlations Table

	Mean	SD	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1 Well-Being	27.55	5.911																
2 Personality *Extraversion*	3.28	1.305	**-.178***															
3 Personality *Agreeableness*	2.68	1.190	**.214***	.136														
4 Personality *Conscientiousness*	2.60	1.097	.149	**.334****	**.390****													
5 Personality *Emotional Stability*	2.92	1.247	-.096	**.190***	**.459****	**.346****												
6 Personality *Openness to Experience*	2.99	1.028	.120	**.370****	**.313****	**.337****	**.196***											
7 Female	.69	.466	**-.273****	-.052	-.077	**-.277****	-.012	.007										
8 Participant's Age *Under 35*	.31	.466	.099	.018	.160	.007	**.179***	.152	.033									
9 Participant's Age *35 - 49*	.64	.480	.002	-.064	-.124	-.028	**-.212***	**-.169***	.002	**-.913****								
10 Participant's Age *Over 50*	.04	.197	**-.237***	.112	-.076	.051	.094	.051	-.083	-.139	**-.277****							
11 Participant's Education - *School or Less*	.21	.410	-.057	.104	.064	.122	.049	**.184***	.084	-.031	.022	.019						
12 Participant's Education - *A-Levels etc*	.36	.483	-.107	.164	-.004	-.022	.094	.045	.012	.078	-.100	.058	**-.392****					
13 Participant's Education - *Degree*	.32	.470	.049	**-.236***	-.082	-.113	-.126	**-.218***	-.046	-.001	.059	-.142	**-.359****	**-.522****				
14 Participant's Education - *Postgraduate/Other*	.10	.302	**.174***	-.036	.046	.046	-.021	.018	-.063	-.082	.038	.101	**-.174***	**-.253***	**-.232***			
15 Lone Carer	.0707	.25764	-.086	.106	-.077	.047	.016	.059	**.186***	.154	-.126	-.057	.146	.119	**-.191***	-.092		
16 Overall Children in Household	2.17	.869	-.138	**-.197***	-.110	-.056	-.073	**-.267****	.033	**-.210***	**.196***	.019	.068	-.102	.088	-.067	.036	

Note: numbers in bold are significantly correlated $p < .05$ = * $p < .005$ = **

Well-Being Regressed onto Individual Differences

The regression analysis with well-being as the criterion variable and personality, participants gender, age, level of education, whether the participant is a lone carer and the overall number of children in the household as the predictor variables revealed that approximately 30% of the variance was explained in this model (R^2 = .30). The data met the assumption of independent errors (Durbin-Watson value = 2.033). However, the generalisability of this model was reduced when applying to a different population as indicated by the adjusted R^2 value (19%). The model itself showed a significant effect (F(13,85)=2.85, p<.005) with the personality subscale extraversion (Beta = -.253, t(98) = -2.43, p < .05), participant gender (Beta = -.246, t(98) = -2.51, p < .05) and the over 50 age group (Beta = -.212, t(98) = -2.23, p < .05) being significant predictors for well-being.

The regression model explains approximately a third of the variance in the well-being of family carers of a child with Down syndrome. Furthermore, the model shows that having lower levels of the personality trait extraversion, being under the age of 50 years old and male predicts higher well-being. In addition, extraversion appears to be is the most significant variable of the three.

Table 6: Individual Differences Coefficients Table

Predictors	Standardized Coefficients Beta	*t*	Sig.
Extraversion	**-.253**	**-2.433**	**.017**
Agreeableness	.191	1.721	.089
Conscientiousness	.116	1.027	.307
Emotional Stability	-.197	-1.830	.071
Openness to Experience	.131	1.216	.227
Female	**-.246**	**-2.519**	**.014**
Under 35 Years Old	.057	.586	.559
Over 50 Years Old	**-.212**	**-2.230**	**.028**
Left School at 16 or Younger	-.003	-.027	.979
Studied to Degree Level	.022	.204	.839
Postgraduate/Other	.151	1.523	.131
Lone Carer	-.007	-.075	.940
Overall Children in Household	-.107	-1.093	.277

Note: items in bold are significant predictors

The Role of Deprivation in the Well-Being of Family Carers

The four predictor variables included in the deprivation regression were hardship and income (dependent on benefits, annual income of less than average, annual income of more than average). The criterion variable was well-being.

Deprivation Correlational Analysis

Initial correlational analysis (Table 7) indicates that well-being did not correlate with any of the entered predictor variables. However, more than average income almost correlated significantly with well-being (r = .165, p = .051).

Intercorrelation Between Deprivation Predictors

From looking at the interpersonal relationship between the predicting variables, hardship correlated significantly with being dependent on benefits/pension and having an income that is below average. Hardship also correlated negatively with having an above average income, suggesting that hardship decreases as income increases. In addition, the sub-scales of income all correlated with each other.

Table 7: Deprivation Correlations Table

		Mean	SD	1	2	3	4	5
1	Well-Being	27.45	5.97					
2	Hardship Index	3.42	2.91	-.058				
3	Dependent on Benefits/Pension	.141	.35	-.158	**.181***			
4	Income Less Than Average	.242	.430	-.059	**.291****	**-.230***		
5	Income More Than Average	.616	.488	.165	**-.386****	**-.514****	**-.717****	

Note: numbers in bold are significantly correlated $p < .05$ = * $p < .005$ = **

Well-Being Regressed onto Deprivation

The regression analysis with well-being as the criterion variable and hardship and income as the predictor variables revealed that approximately 3% of the variance was explained in this model (R^2 = .035). The data did not meet the assumption of independent errors (Durbin-Watson value = 2.307). Furthermore, the generalisability of this model was further reduced when applying to a different population as indicated by the adjusted R^2 value (adjusted R^2 = .004). This model was not significant (F(3,95) = 1.134, p = .340) with no deprivation factors significantly predicting well-being in this sample.

The Role of the Support Needs of the Child in the Well-Being of Family Carers

The eight predictor variables included in the support needs regression were the child's gender, age, severity of disability, support needs and the behaviour scale. The criterion variable was well-being.

Support Needs Correlational Analysis

Initial correlational analysis (Table 8) indicates that well-being significantly negatively correlated with child's age (r = -.433, p < .05) and behaviour (r = -.353, p < .05).

Intercorrelation Between Support Need Predictors

From looking at the interpersonal relationship between the predictor variables, the child's gender correlated significantly with the severity of the disability being mild. This suggests that females are more likely to have mild severity of disability. Child's age group correlated significantly with high level of support needs, proposing that as age increases, level of support needs decreases. Age group also correlated positively with support needs being mild/moderate and the behaviours that challenge scale. Mild severity of disability correlated with support needs suggesting that those with a mild severity of disability have less support needs. In addition, those who were described as having a severe level of disability were associated with having higher behaviours that challenge.

Table 8: Support Needs Correlations Table

		Mean	SD	1	2	3	4	5	6	7	8	9
1	Well-Being	27.59	5.78									
2	Child's Gender	.40	.492	-.037								
3	Child's Age	1.08	1.062	**-.433****	.056							
4	Severity of Disability : Mild	.244	.432	.102	**.216***	-.134						
5	Severity of Disability : Moderate	.581	.495	-.006	-.071	.066	**-.671****					
6	Severity of Disability : Severe	.163	.371	-.103	-.134	.097	**-.252***	**-.521****				
7	Support Needs: High	.551	.499	.071	-.104	**-.319****	**-.202***	.108	.066			
8	Support Needs: Mild/Moderate	.438	.498	-.098	.121	**.340****	**.214***	-.125	-.057	**-.980****		
9	Behaviours that challenge	2.80	2.76	**-.353****	-.056	**.240***	-.115	-.150	.302**	-.056	.077	

Note: numbers in bold are significantly correlated

*p < .05 = ** *p < .005 = ***

Well-Being Regressed onto Support Needs

The regression analysis with well-being as the criterion variable and the child's gender, age, severity of disability, support needs and the behaviour scale as the predictor variables revealed that approximately 26% of the variance was explained in this model (R^2 = .26). The data met the assumption of independent errors (Durbin-Watson value = 2.310). However, the generalisability of this model was reduced when applying to a different population as indicated by the adjusted R^2 value (19%). The model itself showed a significant effect ($F(8,89) = 3.97, p < .001$) with child's age (Beta = -.382, $t(98) = -3.72$, $p < .05$) and behaviour that challenge (Beta = -.259, $t(98) = -2.60$, $p < .05$) being significant predictors for well-being. Child's age appears to be the stronger predictor.

The regression model explains approximately a quarter of the variance in the well-being of family carers of a child with Down Syndrome. Furthermore, the model shows that having a younger child with Down syndrome with lower levels of behaviours that challenge predicted higher well-being in the carers.

Table 9: Support Needs Coefficients Table

Predictors	Standardized Coefficients Beta	t	Sig.
Child's Gender	-.036	-.386	.701
Child's Age	**-.382**	**-3.723**	**.000**
Severity of Disability : Mild	.163	.400	.690
Severity of Disability : Moderate	.159	.347	.729
Severity of Disability : Severe	.137	.395	.694
Support Needs: High	-.337	-.736	.464
Support Needs: Mild/Moderate	-.280	-.604	.547
Behaviours That Challenge	**-.259**	**-2.600**	**.011**

Note: items in bold are significant predictors

Predicting Well-being in Families of a Child with Down syndrome:

Final Regression

The eleven predictor variables included in this regression were family support, social support, resilience, coping sub-scale positive reappraisal, personality sub-scales extraversion and agreeableness, participant gender, over 50 age group, postgraduate education level, child's age and behaviour. The criterion variable was well-being. These variables were entered into this final regression as they all correlated positively with well-being within the first four regression analyses despite some of them not being significant in the actual regression models.

Final Regression Correlational Analysis

Initial correlational analysis (Table 10) indicates that well-being was positively correlated with family support (r = .247, p < .05), social support (r = .214, p < .05), resilience (r = .435, p < .05), positive reappraisal (r = .207, p < .05), extraversion (r = -.172, p < .05), participant gender (r = -.274, p < .05), the over 50 age group (r = -.249, p < .05), child's age group (r = -.425, p > .05) and behaviour (r = -.344, p < .05).

Intercorrelation between Final Predictors

From looking at the interpersonal relationship between the predictor variables, family support correlated significantly with social support, positive reappraisal and extraversion. Social support was associated with having higher resilience and less of the personality trait agreeableness. Having higher resilience was correlated significantly with having less extraversion and agreeableness and children of a younger age group. Furthermore, having a postgraduate level of education, younger children and less behaviours that challenge were all indicators of higher resilience. Correlations also revealed that the higher the child's age group, the higher the behaviours that challenge.

Table 10: Final Regression Correlations Table

	Mean	SD	1	2	3	4	5	6	7	8	9	10	11	12
1 Well-Being	27.61	5.80												
2 Family Support	48.30	12.35	**.247***											
3 Social Support	37.64	8.18	**.214***	**.438****										
4 Resilience	3.53	.811	**.435****	.142	**.312****									
5 Coping: Positive Reappraisal	5.98	4.21	**.207***	**.212***	.114	.072								
6 Personality: Extraversion	3.26	1.32	**-.172***	**-.254***	-.167	**-.45**8**	-.157							
7 Personality: Agreeableness	2.67	1.17	.167	.044	**-.392****	**-.227***	**.175***	.137						
8 Participant Gender	.69	.463	**-.274****	-.160	.019	-.143	-.138	-.056	-.077					
9 Over 50	.042	.201	**-.249***	-.078	-.107	**-.194***	-.012	.116	-.076	-.089				
10 Education: Postgraduate	.094	.294	.152	.086	.085	**.192***	.087	-.052	-.017	-.098	.111			
11 Child's Age	1.09	1.06	**-.425****	-.166	-.096	**-.214***	-.104	.148	-.107	.168	**.378****	-.131		
12 Behaviours That Challenge	2.76	2.77	**-.344****	-.115	-.009	-.085	.144	.086	-.053	.110	-.039	-.038	**.245***	

Note: numbers in bold are significantly correlated $p < .05$ = * $p < .005$ = **

Final Regression Analysis

The regression analysis with well-being as the criterion variable and family support, social support, resilience, coping sub-scale positive reappraisal, personality sub-scales extraversion and agreeableness, participant gender, over 50 age group, postgraduate education level, child's age and behaviour as the predictor variables revealed that approximately 47% of the variance was explained in this model (R^2 = .47). The data met the assumption independent errors (Durbin-Watson value = 2.155). The generalisability of this model was slightly reduced when applying to a different population as indicated by the adjusted R^2 value (40%). The model itself showed a significant effect (F(11,83) = 6.864, p < .001) with resilience (Beta = .348, t(95) = 3.494, p < .05), agreeableness (Beta = .221, t(95) = 2.331, p < .05) and child's behaviour (Beta = -.271, t(95) = -3.164, p < .05) being significant predictors for well-being.

The regression model explains approximately half of the variance in the well-being of family carers of a child with Down syndrome. Furthermore, the model shows that a more resilient carer with a more agreeable personality who had a child with less behaviours that challenge would have higher well-being. Again, resilience appears to be the strongest predictor of well-being whilst the personality trait agreeableness appears to be the weakest of the significant predictors.

Table 11: Final Regression Coefficients Table

Predictors	Standardized Coefficients Beta	*t*	Sig.
Family Support	.019	.193	.847
Social Support	.148	1.423	.159
Resilience	**.348**	**3.494**	**.001**
Coping: Positive Reappraisal	.131	1.504	.136
Personality: Extraversion	.063	.664	.509
Personality: Agreeableness	**.221**	**2.331**	**.022**
Participant Gender	-.135	-1.561	.122
Over 50	-.116	-1.271	.207
Education: Postgraduate	.035	.416	.679
Child's Age	-.168	-1.784	.078
Behaviours That Challenge	**-.271**	**-3.164**	**.002**

Note: items in bold are significant predictors

Summary of Final Regression

Following the first four regressions which were conducted above (psycho-social, individual differences, deprivation and support needs of child), the final regression included all of the predictors which correlated significantly with well-being. The final regression appears to be a strong model with approximately 47% of the variance being explained by this regression analysis. Although some of the variables added into the final regression were not significant predictors of well-being (family support, social support, positive reappraisal, agreeableness, and participant education level), they seem to as a whole add explanatory power in explaining predictors of well-being. This does sit more with previous findings from the literature as social support in particular was highlighted as a key predictor of well-being (Hsiao, 2014) along with positive reappraisal (Van Der Veek et al., 2009).

Chapter 4: Discussion

The aim of this study was to identify the psycho-social factors that predict well-being in families of children with Down syndrome. Particular prominence was placed on exploring the significance of coping styles and the impact of deprivation and hardship on the well-being of these families.

The key findings from the study are highlighted below:

- Resilience appeared to be the strongest predictor of carer's well-being
- The level of the child's behaviours that challenge is a significant predictor of carer's well-being
- The personality subscale 'agreeableness' was a significant predictor of carer's well-being
- Deprivation/hardship was not a significant predictor of well-being

The results of the final regression analysis within this study are discussed below in more detail. Following this, the overall findings of this study are also explored within the four key categories as used throughout the thesis: Psycho-social, individual differences, deprivation and support needs of child.

Final Regression & Exploration of Key Findings

The purpose of this final regression analysis was to include all the variables which correlated significantly with well-being from the first four initial correlational analyses, despite some of them not achieving significance as predictors. The predictor variables included in this regression alongside the criterion variable well-being were: Family support, social support, resilience, coping sub-scale positive reappraisal, personality sub-scales extraversion and agreeableness, participant gender, over 50 age group, postgraduate education level, child's age and behaviour.

With the additional predictors, the model itself explained 47% of the variance. The regression model showed a significant effect with resilience, the personality sub-scale agreeableness and child's behaviour as being predictors of well-being. Resilience appeared to be the strongest predictor in both the preliminary psycho-social regression and the final regression thus supporting findings by Van-Riper (2007) who highlighted the importance of resilience in family functioning and maternal well-being in families of a child with Down syndrome. This in turn adds to existing literature and supports the importance of psycho-social factors in relation to parent/carer well-being.

In this particular context, resilience could perhaps refer to the ability to withstand or recover from difficult or challenging situations that may arise when caring for their child with Down syndrome. Higher resilience can therefore be significant for carers as it can help in maintaining balance in their lives during difficult or stressful periods as well as potentially protecting them from developing physical/mental health difficulties. Higher resilience could also enable carers to protect themselves against overwhelming or challenging experiences, which in turn, can support them in caring for their child. Consequently, this would have a positive impact on the child itself with Down syndrome.

Interestingly, the personality sub-scale agreeableness appeared to be a significant predictor of well-being in this regression model, despite not coming out as a significant predictor within the individual differences regression model. The personality sub-scale extraversion did appear to be a significant predictor within the individual differences regression but agreeableness took precedence as the stronger predictor in the final regression analysis. Agreeableness is a personality trait manifesting itself in individual behavioural characteristics that are perceived as kind, sympathetic, co-operative, warm and considerate (Thompson, 2008).

It has been argued that specifically compared with individuals low on agreeableness, highly agreeable individuals may have higher levels of well-being because they can form and maintain positive and close relationships with others (Bardi and Ryff, 2007). This is in line

with the findings from this study as agreeableness is a significant predictor of higher well-being in carer's of children with Down syndrome. It could be argued that for these carers, being more agreeable could allow for them to form and preserve supportive and encouraging relationships with family, friends and professionals around them when caring for their child with Down syndrome. Thus creating positive outlets and support systems throughout the life span which in turns results in better well-being.

Child's behaviour remained a consistent predictor of well-being as it was also significant within the support needs regression model and the final regression model. This is in line with Bourke et al. (2008) who concluded that raising a child with Down syndrome is not only subject to the same demands faced by families of typically developing children, but also involves additional demands relevant to behavioural challenges. Furthermore, Povee et al. (2012) also found that behavioural challenges were identified by parents/carers of children with Down syndrome as having a negative impact on the family.

This supports the findings from this regression analysis as it shows that more perceived behaviours that challenge results in lower parent/carer well-being. However, a potential issue with this measure may be that this was a subjective measure of how parents/carers perceive their child's behaviour rather than an objective measure of behaviour. Thus, we cannot be clear as to how accurate these findings around behaviours that challenge and well-being may be. The measure used here for behaviours that challenge was a shortened measure as the researcher did not want to overwhelm the participants with too many questions.

Carer's Psycho-Social Factors

The predictor variables included in this regression, alongside the criterion variable well-being, were: Family support, social support, resilience, optimism and coping. Resilience appeared to be the only statistically significant variable within this model thus supporting previous research that examines at strength the resilience of families of children with Down

syndrome. The model indicated that having higher resilience results in better well-being in carers.

Although they did not appear significant within the regression model itself, the variables family support, social support and the coping subscale positive reappraisal, did correlate significantly with carer's well-being. This is in agreement with previous research, that greater social support contributed towards healthier family functioning (Hsiao, 2014) and positive affect in parents of children with Down syndrome (Van Der Veek, 2009). In addition, the coping subscale of positive reappraisal also correlated significantly in previous research with positive affect in parents (Van Der Veek, 2009).

However, although these variables did correlate positively with well-being, they did not appear to be significant in the regression model in the current study. Optimism, as discussed within the literature review, has appeared to be a significant predictor of parental well-being in previous research (Baker et al, 2005), however surprisingly within the present study it was not found to be significant.

The model itself did appear significant, however it should be noted that only 29% of the variance could be explained by this regression model. Therefore 71% is the result of something not accounted for within the analysis. On the whole this model highlights the importance of having high levels of resilience within carers and the positive impact this could have on their well-being. The findings also indicate the importance of having support around the family (whether it be family or social support) and presence of the coping style positive reappraisal.

These findings may be helpful for practice purposes too as it is vital to know how professionals can help to further support families of children with Down syndrome. We can conclude that supporting carer's in building their resilience would be of most importance. Along with ensuring they have the correct support in place and that they are able to use positive coping styles. This is in line with the recommendations made in previous findings for

intervention programs for families of children with Down syndrome in relation to long-term coping strategies (Alexander and Walendzik, 2016).

Carer's Individual Differences

The predictor variables included in this regression analysis alongside the criterion variable well-being were: Personality, participant gender, age, level of education, whether the participant is a lone carer and the overall number of children in the household. The regression model itself was significant and the personality subscale 'extraversion', participant gender and being in the over 50 age group were all significant in predicting well-being. Suggesting that individuals who are male and under the age of 50 have lower levels of the personality trait extraversion and are likely to have better well-being.

In addition to these variables, the personality subscale agreeableness and participant education level of postgraduate/other also correlated significantly with well-being, despite not being significant in the regression analysis. This suggests that having a higher level of education and being more agreeable may also contribute to better well-being.

This supports the argument that individual differences should be considered when exploring families of children with Down syndrome as it can contribute towards differences in well-being. Glidden et al (2006) argued that we know little as to how individual differences such as parental role, personality and other family characteristics effect positive affect in families of children with intellectual disabilities as well as their choice of coping strategies. This supports the justification as to why key variables relating to individual differences were included within this study. Although we cannot change individual differences of carers, it is helpful to consider what aspects of a person can impact well-being. It could also be useful for services to be mindful of some of these aspects if providing support to individuals. Being aware of this information could help inform commissioning of services for example and targeting of health and social supports. It could also be used in training of personnel who

would potentially work with these carers so that they are more aware of this when providing support.

The findings from this particular regression model support this argument from Glidden et al (2006) as individual differences in gender, age and personality have been linked to increasing carer well-being within this model. These findings can be helpful in encouraging us to consider potential differences in the well-being of mothers and fathers of children with Down syndrome. Perhaps tailoring support in relation to gender for families could be helpful as it may be that mothers require additional supports that fathers may not and vice versa.

Research has explored differences in gender when looking at parental well-being and findings have indicated possible gender differences in parental adjustment and coping in relation to their child with an intellectual disability. Olsson (2001) who explored mental health in mothers and fathers of children with intellectual disabilities found that there were clear differences in gender and he concluded that mothers were more at risk of experiencing psychological distress and depression.

It could be possible that the finding of mothers experiencing more distress than fathers is caused by the fact that mothers take on a larger part of the extra care and practical work that the child with disabilities requires (Olsson, 2001). This finding is in line with the significant predictor of gender from this regression model which suggests that fathers have better well-being than mothers.

The participant's age is also a factor that has been significant in predicting well-being in that individuals under the age of 50 years old statistically have better well-being. This may be in relation to the individual differences of that particular person with the potential of them having their own additional needs over the age of 50, as well as caring for their child/adult with Down syndrome. This could also be explained by the amount of support they have for their child with Down syndrome. Perhaps there may be more support available for the child and the family when the child is younger, but this may decrease the older the child becomes.

Furthermore, these findings support the research conducted by Nelson-Goff et al., (2016) who found that parental coping strategies may vary over different points of the life span. They also found that parents who were during the middle stages of life span indicated better coping strategies.

These findings highlight the importance of ensuring there is effective support in place for young and older carers of children with Down syndrome as there may be a tendency for older carers to be overlooked. This could be the result of assuming that they 'know what they are doing' or they have 'had all the support possible'. It may be that as the child progresses into adulthood, their additional needs may change and caring for them may become more challenging for the carer.

Again, only 30% of the variance could be explained by this regression analysis which highlights that individual differences alone do not account for variations in well-being.

Deprivation in Carers

The predictor variables included in this regression analysis alongside the criterion variable well-being were hardship and participant annual income. The initial correlational analysis revealed that well-being did not correlate with any of the predictor variables entered and furthermore the regression model itself did not show a significant effect, with only 3% of the variance being explained by this model. Having said this, having an 'above average' income did almost correlate significantly with well-being (r = .165, p = .051).

A possible explanation for this non-significant model may be in relation to the distribution of income within the data set (see appendix 2). 61% of participants were in the 'above average' category, whereas 24% were earning less than average and the remaining 14% were dependant on benefits/pension. It could also be considered that perhaps participants may have felt 'under pressure' when answering some of the questions related to hardship and in addition they may not have wanted to disclose true income in the fear of being judged.

Furthermore, maybe more questions in relation to hardship and deprivation may have been needed to gain a better understanding of well-being in relation to deprivation.

The model overall contradicts findings from previous research which has suggested that economic hardship does contribute towards parental well-being (Olsson & Hwang, 2008). Within their study, Olsson & Hwang (2008) used the same hardship measure, however they found that differences in economic hardship were the strongest predictors of well-being. They did have a similar sample size (64 mothers and 49 fathers); however they did collect additional information relating to monthly income, expenditure and household composition. This could be a recommendation for future research exploring well-being in relation to deprivation and hardship of families with a child with Down syndrome.

The Child's Support Needs

The predictor variables included in this regression analysis alongside the criterion variable well-being were the child's gender, age, severity of disability, support needs and behaviour. The regression model was significant with the child's age and behaviour both being significant predictors for carer's well-being. Although this model was significant, only 26% of the variance could be explained by it.

Along with behaviours that challenge, the child's age group is also statistically significant in predicting carer well-being and it is the stronger predictor of the two. The regression model shows that having a younger child with Down syndrome predicted higher well-being in carers. Fidler et al (2000) identified that having a younger child with Down syndrome would negatively influence family functioning. This is contradictory to the findings from this study as it appears that the younger the child, the higher the parental/carer well-being.

A possible explanation for this could be that parents/carers of younger children with Down syndrome may receive more support from family/friends as well as services. Similarly to the regression model for individual differences, it was considered that perhaps the older the child/adult with Down syndrome becomes, the less support there may be available for them.

Therefore resulting in more challenges for the parents of older children, causing them a reduced well-being. Whereas the younger child may receive more support which leads to higher well-being in carers.

Although only a small amount of variance in this model was explained by the factors included, it is worth noting that there are fewer factors in this model in comparison to some of the other regression models in this study. Yet the level of variance of this model is quite similar to those of the previous models which have more factors included (i.e. psycho-social regression and individual differences).

Summary

A number of variables correlated significantly with well-being, however, they did not appear to be significant predictors within the regression itself. These variables were: family support, social support, the coping subscale positive reappraisal and participant education level of postgraduate/other. Potential explanations for why these variables may not have been significant include the sample size being insufficiently large to pick up moderate to small, yet potentially significant effects of predictors. Linked to this, perhaps the inclusion of a large number of variables to a relatively small sample size. A second potential explanation is that due to the small sample size and single geographical location for the study, perhaps the carer respondents were more homogenous than might have been expected and hence did not vary sufficiently on particular variables for them to have an effect.

Conducting the regression analysis in four stages to begin with was helpful as the variables were grouped together based on commonality and past literature. As there were a large number of variables, separating them into categories enabled the stronger predictors to be identified along with eliminating the weaker ones. From the first four regressions, it was clear that psycho-social factors along with individual differences were vital in exploring parent/carer well-being. Support needs of the child were also essential to consider, however

deprivation did not appear to contribute towards the well-being of parents/carers in this particular sample.

Resilience in particular appeared to be consistently the strongest predictor throughout the data analysis. This was a particularly interesting finding as research around families of children with Down syndrome has not identified resilience as a key predictor of well-being. Social support, coping and optimism (Van Der Veek, et al., 2009; Baker et al., 2005) have in past literature been strongly linked to well-being of families of children with Down syndrome however, they did not appear significant in the final regression model within this study.

Furthermore, deprivation, which was hypothesised as a main predictor of carer well-being, also appeared non-significant despite literature stating otherwise (Emerson et al, 2006; Olsson & Hwang, 2008). However, similar findings were made in relation to individual differences in that personality, gender and age were significant predictors of well-being (Glidden et al, 2009) and also the behaviour of the child.

The findings from the current study do contribute to the existing field of literature around well-being of families of children with Down syndrome. This is based on the fact that we can begin to understand in more detail which factors are important in carers functioning well as well as the well-being of the child with the disability. We can take some of the existing findings and the results from this study to look at what additional supports may be required for these families to enable them to improve their well-being. For example, resilience focused interventions for carers, perhaps more support for carers with older children/adults with Down syndrome, additional support for behaviours that challenge or perhaps parenting support for managing the behaviour.

Overall, the findings from this study could be applied to practice, particularly in relation to the mental health of carers and overall family functioning.

Limitations

The main limitation of this research was the sample size as this was initially constructed to be a large scale mixed methods study. Based on the number of variables that were in this study, the expected number of participants was greater than the number that was in fact recruited. However, to account for this, the variables were separated into 4 categories before undertaking the final regression analysis. In addition, the intention was to obtain 10-15 additional participants who had experienced high levels of deprivation to take part in the qualitative component of this study which would have been analysed using thematic analysis. However, this was not achieved as a result of the participant sample, with too few people living in more deprived circumstances, which limited the overall findings. However, the trends here are interesting and may benefit from further exploration.

Recruitment of participants proved difficult, as relying on support groups which only met once a month was challenging for arranging times to collect data. In addition, many of the family members who attended these groups were also present with their child/children which made it difficult for some to fully complete their questionnaires during the meetings. Some family members agreed to take their questionnaires home to complete and post to the researcher but unfortunately these questionnaires were not received. This is illustrative of the burden on time which being a carer of a young child, and in particular a young child with an intellectual disability can present.

Another limitation in relation to participants is that the study proposed to explore well-being of families of children with Down children and therefore family members who were not the mother or father of the child were also included within the participant sample. This was initially decided as there were concerns around recruitment and achieving an adequate sample size to conduct the analysis, a concern which was borne out in the study, therefore the researcher did not want to limit the participants to mothers/fathers only. In hindsight, the inclusion criteria may have been better being more specific with participant being only the primary carer for the individual with Down syndrome. Family members who are not primary

carers may have a very different perspective on certain aspects of life, such as support, as well as fewer responsibilities which may have affected the findings here and is a consideration for future research to consider.

Furthermore, questionnaires from more than one member of the same family were included within the sample as questionnaires were handed to as many people who wanted to participate within the groups. As the questionnaires were anonymous, this made it difficult to identify which questionnaires were related to the same individual with Down syndrome, therefore the results may not be based on 100 children/adults with Down syndrome. Evidently, this may have had an impact on the results within this study and is a point of learning for conduct of future studies in this area.

LaPiere (1934) indicated that attitudes on a questionnaire do not always reflect actual behaviour therefore triangulating the survey findings with a qualitative element within the study would have increased the robustness of the study and the interpretability of the findings. A qualitative component may also have highlighted alternative factors that may play a significant role in well-being.

In relation to the questionnaire itself, a limitation here was the accidental errors which were made when transferring the instrument into the composite survey for participants. The SF-8 scale had a missing item and a duplicated item. The behaviours that challenge scale also had a duplicated item and the layout of questionnaires themselves were reformatted which may have affected the way in which they were interpreted and completed by participants. Consequently, these mistakes may have had a significant impact upon the results within this study, which should be taken into consideration when interpreting the study findings.

Furthermore, it was noted that some participants circled the descriptors at the end of the scales rather than the actual numbers. This may suggest that participants misinterpreted some of the response scales and therefore scored the questionnaire incorrectly.

Consequently, this may have had an impact on the validity of the results and this should be taken into account when exploring the findings from this study.

Another limitation within this study was the measurement of the deprivation element of the study. Deprivation was hypothesised as being a significant predictor of well-being based on literature from previous research (Emerson et al, 2006; Olsson & Hwang, 2008). However, it appeared to be non-significant within the regression analysis for this study. Upon reflection, the index for hardship may not have been a clear measure of the participants' socio-economic situation, as described within the methodology chapter.

In addition, the actual items for the measure may have created some confusion as the middle response option 'we do not want/need this at the moment' may have been reflective of less deprivation than the top response of 'we have this' as a family may not have wanted a particular item even if they could afford it.

Hence a different measure of deprivation/hardship may have been more effective in exploring the impact of socio-economic situation on well-being. The non-significance of deprivation may have also been due to the fact that all participants were from a similar geographic location, who may have more homogenous supports from the external agencies and are likely to be in a similar financial position. This could be supported by the fact that the majority of the sample from this study were all earning above the average income bracket. Furthermore, this may highlight the issue that perhaps deprivation/hardship does not work as a variable by itself and may instead predict well-being in interaction with other variables.

The present study may also have been improved by taking into account financial support that a significant extended family member (i.e. parents/grandparents) may have provided. However, overall deprivation may only be a significant predictor with larger more heterogeneous samples across a wider geographical location. This last point seems particularly important given the lack of variation in income in the present sample, with only 24% of participants reported being in the lower income category (see appendix 2).

Recruitment of participants from a lower socio-economic background was challenging in this study due to the limited access to the sample group which may also have affected the above findings.

Future Research

Carrying out research provides a platform for the development of new research areas and the opportunity to improve methods of data collection. With this in mind, several limitations above have been revealed within this research study that may be overcome in future studies which alter methodology and recruitment processes.

A basic area for future research would be to replicate this study over a longer period of time using a larger sample size. This will enable issues around homogeneity in the sample to be eradicated and it will account for the large number of variables being explored within the study. Conducting this piece of research over a longer period of time may enable the researcher to look at well-being and family functioning as the age of the child increases along with the age of the carer. This may highlight similarities or differences in factors that impact well-being of families. Changes in support systems and income could also be taken into account over a longer period.

It may also be useful for the sample to be conducted across a wider geographical spread to eliminate sample similarities and to ensure a more diverse sample. It may be helpful to consult with participants during the design phase of the research in order to establish what is important to them in relation to well-being. Furthermore, by using more participatory research approaches participants could be more involved in identifying the research topic of interest and designing the study, to better ensure that the variables studied are grounded in what is important contemporaneously in addition to empirically of prior interest academically. Such participatory approaches may also help enhance participant recruitment by having increased legitimacy and relevance of the study to carers, particularly as this was a limitation and challenge in the present study.

Taking into account that not all of the variance was explained by the regression models within this study, it may be useful to consider what factors may account for this unexplained variance and perhaps to include these factors in replicated studies. Future research may consider including factors such as, the impact of having additional children within the family on well-being or the impact of additional family members. Further individual factors such as job stress, diet or sleep could also be explored.

In relation to the limitations around deprivation, it could be suggested that future research could look at specifically recruiting participants from a lower socio-economic background. This would enable the researcher to explore the impact of deprivation in full without relying on random variation in the sample. Future research may also want to consider using more robust and unambiguous measures for deprivation. The measure of well-being could benefit from being separated and explored in detail in terms of mental well-being and physical well-being. If research is able to explore factors that perhaps impact mental health well-being then this could contribute towards mental health support for parent/carers of children with intellectual disabilities. It may be that findings can help in developing additional support groups or individual services for parents/carers along with support for the child with Down syndrome as well.

Continuing with the theme around mental health, it may also be useful for research to explore resilience and coping further in relation to parent/carers of children with Down syndrome. This could be done using qualitative approaches as well as quantitative and this would help in giving carers a platform to share ideas of how they would like to be supported. This could help build on mental health support groups for parent/carers particularly around building and maintaining resilience and helpful coping strategies. As well as making changes methodologically and within the recruitment process for future research, it may also be helpful to do a further more systematic review of the literature in order to better understand the available literature.

Clinical Implications

The overall aim of this study has been to identify the factors that impact well-being of individual carers as well as families of children/adults with Down syndrome. By doing so, the intention is to increase awareness around what leads to better well-being for these individuals and furthermore what could be done to improve well-being. This could be support in the form of individual support, group support, social support, support for the child or even financial support.

As it has been highlighted in the present study, resilience appears to be a significant factor when it comes to well-being in that the more resilient a parent/carer is the better their well-being becomes. With this in mind, resilience focused interventions may be beneficial for these parent/carers. Nash et al (2016) developed a pilot study to test an intervention to enhance resilience and self-efficacy in parents who have a child with a disability or complex health needs. They concluded that the initial findings were very positive with parents welcoming the intervention. The qualitative feedback highlighted the significance of this intervention for parents, with one parent stating, “I always do my best but you know, you don’t feel good about yourself, whereas this is, you know, my session yesterday I actually felt on top of the world, I haven’t felt that good in ages”. This highlights the potential importance of such interventions.

In addition to resilience based interventions, perhaps varying the support available for carers at different life stages could be considered (Nelson-Goff et al., 2016). As found in the present study, well-being appears to be lower in carers over the age of 50, therefore perhaps more support and interventions may be needed for older carers. Support could also be tailored around not only the age of the carer, but also the age of the child. As the child begins to get older and develop into an adult, it may be that different types of support and interventions could be required.

By increasing the understanding of the factors that contribute towards the overall well-being of carers of children with Down syndrome, as professionals we are in a better position to begin to provide care and support for these families. In particular, I believe that counselling psychologists' skills are ideal for contributing towards providing and developing holistic and therapeutic interventions for these families. As outlined in the Division of Counselling Psychology Professional Practise Guidelines, Counselling Psychologists must make themselves knowledgeable about the diverse life experiences of the clients they work with and consider at all times their responsibilities to the wider world.

The present research study would assist Counselling Psychologists in being able to practice in this way as we are able to reflect on the impact of life experiences of carers of children with Down syndrome. By doing so, practitioners are able to consider what increases well-being in carers and in turn facilitate person-centred personal interventions based on this existing research. The results of this study may influence Counselling Psychologists to focus more on building resilience in carer's either within group settings or individual settings. Furthermore, it may encourage practitioners to consider in more detail personality traits of carers and the impact this may have on their overall well-being.

As part of a Counselling Psychologist's continuing professional development, practitioners are encouraged to keep abreast of current literature and the profession overall is to be practice led with a research base grounded in professional practice values as well as professional artistry. Taking this into account, this present study may be of great relevance to Counselling Psychologists, particularly those working directly with either carer's of children with Down syndrome or other intellectual disability as well as children/adults with Down syndrome themselves. Therapeutically this study could assist in considering the wider aspects of an individual's well-being, such as, individual differences and psycho-social factors.

Whilst this research study could hopefully be of great use for professionals supporting families of children with Down syndrome, it is also of value for these families and individuals

with Down syndrome themselves. As discussed throughout the research, there are mixed messages in terms of the impact having a child with Down syndrome will have on individual carers and families. Some studies have found the impact to be detrimental whilst others have concluded that these families function as 'normal'.

The aim of this particular study was to enable the voices of these families to be heard and to highlight first-hand what impact's their personal well-being. Whilst this research adds to the existing knowledge base of intellectual disabilities, most importantly it adds specifically to the understanding we have of families of children with Down syndrome. The information we have learnt throughout this process will hopefully encourage professionals to customise and tailor support for families of children with Down syndrome as well as individuals with Down syndrome themselves. This is particularly of importance in the current economical/political climate with the impact of underfunding and on-going cuts to some services. The impact of this may mean that interventions need to be shorter and therefore more specific to the needs of carers in order to be effective.

Concluding Summary

This study was developed to explore the psycho-social factors that impact well-being the families of children with Down syndrome, alongside focusing on the impact of individual differences and deprivation. The key findings from this research indicate that higher levels of resilience lead to higher well-being in family members. In addition, being a male carer, with a younger child with Down syndrome who has lower levels of behaviours that challenge is predictive of better well-being. Although not all factors were found to be significant overall, this study does highlight the importance of psycho-social factors and individual differences in the carer and child in relation to well-being. Finally, the findings suggest that the impact of deprivation and carer hardship on well-being could be an area of further research.

Chapter 5 – Critical Appraisal

This chapter provides a reflective critical appraisal of the research process and the decisions made during the research journey. In addition, I discuss how the research findings may contribute to the knowledge base of counselling psychology.

As mentioned in the very beginning of this thesis, my interest in Down syndrome stems from my own personal experiences of growing up with a brother with Down syndrome. Given that he is only 4 years younger than me, he has been a significantly big part of my life so far and shaped who I am as a person today. From this experience of growing up with a sibling who not only had an intellectual disability but also a number of medical conditions, I was always very mindful of how my family around me were coping, particularly my parents. This way of thinking always stayed with me and even influenced my undergraduate dissertation where I researched coping in parents of children with Down syndrome. This allowed me to gain a wider understanding of not only my own parents but also other parents of children with Down syndrome and different ways of coping they may have.

Upon beginning my postgraduate studies on the Counselling Psychology Doctorate course, I still had a keen interest in the field of learning disabilities, particularly the support network and families around these individuals. This is what led me to continue my exploration of families of children with Down syndrome, but this time to consider other factors that may contribute towards well-being as well as coping.

I had initially hoped of doing a qualitative study as this is the methodology I used for my undergraduate dissertation and it was an approach I was comfortable with. However, after looking into past research around this topic and discussing this with my fellow peers and lecturers, I was able to see the benefit of perhaps undertaking a mixed methods study instead. The initial process of planning the structure of the study was quite exciting, particularly as I felt I already had a fairly good understanding of Down syndrome and the families around these individuals. However, I was conscious of my closeness to the research

project and needing to be aware of my own experiences and assumptions. It was important that I bracketed my personal reflections but also value these as the role of the researcher (Giorgi, 1985).

The process of conducting the study itself then became quite overwhelming, particularly on top of the academic process as a whole and the additional course requirements. In addition, I was also experiencing some familial difficulties during this process which made it challenging at times to move forward with the research process. However, being able to have my own personal therapy at the same time helped in being able to focus and plan ahead with aspects of my personal, work and academic life.

Once I had actually started collecting data, I found that I was beginning to enjoy the process a lot more and I felt quite hopeful. However, during this process I realised that the response rate for the qualitative component of the study was quite low which caused a lot of worry and stress. At this stage I had to start re-evaluating my options and it was decided that I would continue with the study as a quantitative piece of research instead. The next stage of data analysis was probably the biggest stumbling block for me particularly due to my anxieties around using SPSS and interpreting statistics. Although this process was initially discomforting for me, I was able to overcome this once I spent some time revisiting quantitative methodology.

During the writing stages of my research, I was able to actually step back and process the intriguing nature of my research. Although I had gone into this with my own experiences of families of children with Down syndrome, I was able to learn so much more from the outcome of my survey in the study as well as the new literature I was coming across. However, one of the difficulties I came across was trying to make sense of the interaction between different factors of interest. Particularly as my interest previously was around coping, so beginning to look at different factors was captivating. My supervisory meetings were invaluable to me during the entire process as my supervisors helped me to reflect and consider things I had perhaps not been able to think about myself.

The findings from this study became very relevant within my journey of becoming a counselling psychology. Particular the notion of working holistically and in a person-centred manner as I have been able to adopt this way of thinking within my research. One of my main aims upon beginning this journey was to increase the amount of support available for families of children with Down syndrome with particular emphasis placed on the type of support they receive. Especially as all intellectual disabilities are quite different therefore support needs to be tailored. I hope that the findings from this study will contribute towards tailoring support specifically for these families and perhaps even differentiating the support for mothers, fathers and even siblings.

As a counselling psychologist, I hope to be able to contribute towards the future support that will be available for families of children with Down syndrome. This is particularly important for me as I know from personal experiences and from my experiences in conducting this research that support around these families is imperative. Furthermore, helping families to build on existing coping strategies and inner strength/resilience will be beneficial for the young person with Down syndrome as well as family members.

Despite some of the difficulties I have faced during the research process, I feel I have gained a lot from this study as a student, professional and as a sister. It has been a time of growth and reflection which has resulted in me developing in confidence not only as a practitioner but also as a researcher. I felt at times that this journey was impossible and that I would never reach the finish line. However, I have learnt to not worry so much about the finish line but to instead allow myself to pass through the journey one step at a time.

Research Dossier Word Count – 21,905.

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Appendices

Appendix 1

Demographic Information of Family Member with Down syndrome

Variable		%	N
Gender of family member with Down syndrome (N = 100)	Male	60%	60
	Female	40%	40
Age Group (N = 99 reported, 1 missing)	0-4	38%	38
	5-9	28%	28
	10-14	23%	23
	15-19	8%	8
	20-34	2%	2
Living arrangements of family member with Down syndrome (N = 100)	Home with family	98%	98
	Residential services	1%	1
	Independent	1%	1
Severity of disability (N = 98 reported. 2 missing)	Mild	25%	25
	Moderate	57%	57
	Severe	16%	16

Appendix 2

Demographic Information for Household

Variable		%	N
Total number of children in household (N = 99 reported, 1 missing)	1	23%	23
	2	43%	43
	3	26%	26
	4	7%	7
Participants highest level of education (N = 100)	Left school at 16 years or younger	22%	22
	A Levels/BTEC/Foundation etc	36%	36
	University Degree	32%	32
	Postgraduate study	10%	10
Family home location (N = 94 reported. 6 missing)	Urban	90%	90
	Rural	4%	4
Household income (N = 99 reported, 1 missing)	Dependant on benefits/pension	14%	14
	Less than £23,200	24%	24
	More than £23,200	61%	61

Appendix 3

Factors That Predict The Well-Being Of Families Of Children With Down Syndrome.

Introduction

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends/relatives. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

You are being asked to take part in a research study exploring factors that affect well-being of families of children with Down syndrome. This study is being undertaken by Jaspreet Uppal, a Counselling Psychology Doctorate student from the University of Wolverhampton under the supervision of Dr. Darren Chadwick and Dr. Josephine Chen-Wilson.

Why have I been chosen?

Because you are a family members of children and adult children with Down syndrome and we are interested in exploring your views and experiences.

Do I have to take part?

Your participation in this study is entirely voluntary. Before agreeing to take part you must read this information sheet in full and sign a consent form confirming that you agree to take part, both of which you will have a copy of to keep. If you change your mind and do not wish to take part, you are free to withdraw at any point, whether before, during or after the study. You can withdraw by July 2014 by contacting the researcher.

What will happen if I decide to take part?

If you agree to take part in this study you will be asked to complete a questionnaire, which will take approximately 20 - 30 minutes to complete. The questionnaire contains mainly closed questions, which require you to select the answer that best suits you for each question.

Will my taking part in the study be kept confidential?

Your responses to the questionnaire, if you agree to take part, will be treated with the strictest confidentiality. Due to the nature of the research, your responses will be examined by the researcher and her supervisors and included in the final report; however, all responses will be kept confidential. The data in the final report will be grouped together so no individual person's responses will be identifiable. To further protect your anonymity, any personal identifiable information mentioned within the questionnaire, such as names,

places and organisations will be changed. The only situation under which information may be shared is if there is a safeguarding issued raised around which you may need support.

What will happen to the information which you give?

The questionnaire responses will be kept in the possession of the researcher for a period of 2 years in order to give sufficient time for the research to be written up and shared, after this time it will be destroyed.

What will happen to the results at the end of the study?

The anonymised results will be presented in the research student's final thesis. The whole thesis, including the results will be seen by the researcher's supervisors, and her examiners. The thesis may be read by future students, and findings may also be published in a research journal. If you wish to receive a summary of the findings or get an electronic copy of the whole final thesis, you can contact the researcher after July 2014.

What are the possible advantages and disadvantages of taking part?

Published results may help to inform and shape supports for families of individuals with Down syndrome in the future so that they better meet the needs of parents. The researcher does not envisage any negative consequences in you taking part in this research; however, due to the nature of the research, the questionnaire may include questions that cause you to reflect on an upsetting event in your life which may lead to distress. If this happens you are free to choose whether or not you wish to continue participating.

Who has reviewed the study?

Wolverhampton Research Ethics Committee has reviewed and approved this study and it is sponsored by Wolverhampton University.

What if there is a problem or I have any further queries?

Upon completing the questionnaire, the researcher will provide a list of organisations you could contact if you feel you need further support or you can contact the researcher for further information on this. If you have a problem with the study, or any questions, you can contact the research student Jaspreet in the first instance or Jaspreet's supervisor Dr. Darren Chadwick.

If you agree to take part in this study then please read, sign and date the consent form.

Consent Form

Factors That Predict The Well-Being Of Families Of Children With Down Syndrome.

Researcher- Jaspreet Uppal

Supervised by Dr Darren Chadwick and Dr Josephine Chen-Wilson

Please Initial Boxes

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw until the data analysis begins without giving any reason. ☐
3. I understand that my data will be stored securely and confidentially and that I will not be identifiable in any report or publication. ☐
4. I understand that the researcher may wish to publish this study and any results found for which I give my permission. ☐
5. I agree for the data from my questionnaire/interview to be used for the purpose of this study. ☐
6. I agree to take part in the above study. ☐

Name……..Date……..Signature……

Researcher……..Date……..Signature……

Thank you for agreeing to take part in this research study. You will now be required to complete the following questionnaire. Please ensure all answers are your own and please be as honest and open as you can.

The Support You Receive

Please circle the response that best describes how helpful the following sources have been to your family in terms of raising your child with Down syndrome during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, circle the NA (Not Available) response.

How helpful has each of the following been to you in terms of raising your children?

Source of help/support	Not Available	Not at all Helpful	Sometimes Helpful	Generally Helpful	Very Helpful	Extremely Helpful
My family	0	1	2	3	4	5
My spouse or partners parents	0	1	2	3	4	5
My relatives/kin	0	1	2	3	4	5
My spouse or partners relatives/kin	0	1	2	3	4	5
Spouse or partner	0	1	2	3	4	5
My friends	0	1	2	3	4	5
My spouse or partners friends	0	1	2	3	4	5
My own children	0	1	2	3	4	5
Other parents	0	1	2	3	4	5
Co-workers	0	1	2	3	4	5
Parents groups	0	1	2	3	4	5
Social groups/clubs	0	1	2	3	4	5
Church members/minister	0	1	2	3	4	5
My family or child's physician	0	1	2	3	4	5
Early childhood intervention program	0	1	2	3	4	5
School/day-care centre	0	1	2	3	4	5
Professional helpers (social workers, therapists, teachers etc.)	0	1	2	3	4	5
Professional agencies (public health, social services, mental health etc.)	0	1	2	3	4	5
Other (please describe)	0	1	2	3	4	5
Other (please describe)	0	1	2	3	4	5

More Questions About You And The Support You Receive

Please read each statement carefully and circle the number which best describes your answer.

I participate in volunteer/service projects	Not at all true	0	1	2	3	Completely true
I have meaningful conversations with my parents and/or siblings	Not at all true	0	1	2	3	Completely true
I have a mentor(s) in my life I can go to for support/advice	Not at all true	0	1	2	3	Completely true
I rarely invite others to join me in my social and/or recreational activities	Not at all true	0	1	2	3	Completely true
There is no one I can trust to help solve my problems	Not at all true	0	1	2	3	Completely true
I take time to visit with my neighbours	Not at all true	0	1	2	3	Completely true
If a crisis arose in my life, I would have the support I need from family and/or friends	Not at all true	0	1	2	3	Completely true
I belong to a club (e.g. sports, hobbies, support group etc)	Not at all true	0	1	2	3	Completely true
I have friends from work that I see socially (e.g. movie, dinner, sports, etc)	Not at all true	0	1	2	3	Completely true
I have friendships that are mutually fulfilling	Not at all true	0	1	2	3	Completely true
There is no one I can talk to when making important decisions in my life	Not at all true	0	1	2	3	Completely true
I make an effort to keep in touch with friends	Not at all true	0	1	2	3	Completely true
My friends and family feel comfortable asking me for help	Not at all true	0	1	2	3	Completely true
I find it difficult to make new friends	Not at all true	0	1	2	3	Completely true
I look for opportunities to help and support others	Not at all true	0	1	2	3	Completely true
I have a close friend(s) whom I feel comfortable sharing deeply about myself	Not at all true	0	1	2	3	Completely true
I seldom get invited to do things with others	Not at all true	0	1	2	3	Completely true
I feel well supported by friends/family	Not at all true	0	1	2	3	Completely true
I wish I had more people in my life that enjoy the same interests and activities as I do	Not at all true	0	1	2	3	Completely true
There is no one that shares my beliefs and attitudes	Not at all true	0	1	2	3	Completely true

How You Cope

Please think of a stressful situation/encounter you have experienced over the past 6 months involving your child with Down syndrome.

Please now read each item below and indicate by circling the appropriate number adjacent to each item, to what extent you used it in the situation you are thinking of.	**Not Used**	**Used Some-what**	**Used Quite a bit**	**Used a Great Deal**
Just concentrated on what I had to do next – the next step	0	1	2	3
I tried to analyse the problem in order to understand it better	0	1	2	3
Turned to work or substitute activity to take my mind off things	0	1	2	3
I felt that time would make a difference - the only thing to do was to wait	0	1	2	3
Bargained or compromised to get something positive from the situation	0	1	2	3
I did something which I didn't think would work, but at least I was doing something	0	1	2	3
Tried to get the person responsible to change his or her mind.	0	1	2	3
Talked to someone to find out more about the situation	0	1	2	3
Criticized or lectured myself	0	1	2	3
Tried not to burn my bridges, but leave things open somewhat	0	1	2	3
Hoped a miracle would happen	0	1	2	3
Went along with fate; sometimes I just have bad luck	0	1	2	3
Went on as if nothing had happened	0	1	2	3
I tried to keep my feelings to myself	0	1	2	3
Looked for the silver lining, so to speak; tried to look on the bright side of things	0	1	2	3
Slept more than usual	0	1	2	3
I expressed anger to the person(s) who caused the problem	0	1	2	3
Accepted sympathy and understanding from someone	0	1	2	3
I told myself things that helped me to feel better	0	1	2	3
I was inspired to do something creative	0	1	2	3
Tried to forget the whole thing	0	1	2	3
I got professional help	0	1	2	3
Changed or grew as a person in a good way	0	1	2	3
I waited to see what would happen before doing anything	0	1	2	3
I apologized or did something to make up	0	1	2	3
I made a plan of action and followed it	0	1	2	3
I accepted the next best thing to what I wanted	0	1	2	3
I let my feelings out somehow	0	1	2	3
Realized I brought the problem on myself	0	1	2	3
I came out of the experience better than when I went in	0	1	2	3
Talked to someone who could do something concrete about the problem	0	1	2	3
Got away from it for a while; tried to rest or take a vacation	0	1	2	3
Tried to make myself feel better by eating, drinking, smoking, using drugs or medication, etc.	0	1	2	3

Please now read each item below and indicate by circling the appropriate number adjacent to each item, to what extent you used it in the situation you are thinking of.	**Not Used**	**Used Some-what**	**Used Quite a bit**	**Used a Great Deal**
Took a big chance or did something very risky	0	1	2	3
I tried not to act too hastily or follow my first hunch	0	1	2	3
Found new faith	0	1	2	3
Maintained my pride and kept a stiff upper lip	0	1	2	3
Rediscovered what is important in life	0	1	2	3
Changed something so things would turn out all right	0	1	2	3
Avoided being with people in general	0	1	2	3
Didn't let it get to me; refused to think too much about it	0	1	2	3
I asked a relative or friend I respected for advice	0	1	2	3
Kept others from knowing how bad things were	0	1	2	3
Made light of the situation; refused to get too serious about it	0	1	2	3
Talked to someone about how I was feeling	0	1	2	3
Stood my ground and fought for what I wanted	0	1	2	3
Took it out on other people	0	1	2	3
Drew on my past experiences; I was in a similar situation before	0	1	2	3
I knew what had to be done, so I doubled my efforts to make things work	0	1	2	3
Refused to believe that it had happened	0	1	2	3
I made a promise to myself that things would be different next time	0	1	2	3
Came up with a couple of different solutions to the problem	0	1	2	3
Accepted it, since nothing could be done	0	1	2	3
I tried to keep my feelings from interfering with other things too much	0	1	2	3
Wished that I could change what had happened or how I felt	0	1	2	3
I changed something about myself	0	1	2	3
I daydreamed or imagined a better time or place than the one I was in	0	1	2	3
Wished that the situation would go away or somehow be over with	0	1	2	3
Had fantasies or wishes about how things might turn out	0	1	2	3
I prayed	0	1	2	3
I prepared myself for the worst	0	1	2	3
I went over in my mind what I would say or do	0	1	2	3
I thought about how a person I admire would handle this situation and used that as a model	0	1	2	3
I tried to see things from the other person's point of view	0	1	2	3
I reminded myself how much worse things could be	0	1	2	3
I jogged or exercised	0	1	2	3

More Questions About You - How You Feel About Yourself And Your Life

Please indicate the extent to which you agree or disagree with the following statements by circling a number 1 to 7 next to each statement. You should rate the extent to which the traits apply to you, even if one characteristic applies more strongly than the other. Please answer all the questions.

I tend to bounce back quickly after hard times.	Strongly Agree	1	2	3	4	5			Strongly Disagree
I have a hard time making it through stressful events.	Strongly Agree	1	2	3	4	5			Strongly Disagree
It does not take me long to recover from a stressful event.	Strongly Agree	1	2	3	4	5			Strongly Disagree
It is hard for me to snap back when something bad happens.	Strongly Agree	1	2	3	4	5			Strongly Disagree
I usually come through difficult times with little trouble.	Strongly Agree	1	2	3	4	5			Strongly Disagree
I tend to take a long time to get over set-backs in my life.	Strongly Agree	1	2	3	4	5			Strongly Disagree
I see myself as extraverted, enthusiastic.	Strongly Agree	1	2	3	4	5	6	7	Strongly Disagree
I see myself as critical, quarrelsome.	Strongly Agree	1	2	3	4	5	6	7	Strongly Disagree
I see myself as dependable, self-disciplined.	Strongly Agree	1	2	3	4	5	6	7	Strongly Disagree
I see myself as anxious, easily upset.	Strongly Agree	1	2	3	4	5	6	7	Strongly Disagree
I see myself as open to new experiences, complex.	Strongly Agree	1	2	3	4	5	6	7	Strongly Disagree
I see myself as reserved, quiet.	Strongly Agree	1	2	3	4	5	6	7	Strongly Disagree
I see myself as sympathetic, warm.	Strongly Agree	1	2	3	4	5	6	7	Strongly Disagree
I see myself as disorganised, careless.	Strongly Agree	1	2	3	4	5	6	7	Strongly Disagree
I see myself as calm, emotionally stable	Strongly Agree	1	2	3	4	5	6	7	Strongly Disagree
I see myself as conventional, uncreative.	Strongly Agree	1	2	3	4	5	6	7	Strongly Disagree

In uncertain times, I usually expect the best	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
It's easy for me to relax	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
If something can go wrong for me, It will	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I'm always optimistic about my future	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I enjoy my friends a lot	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
It's important for me to keep busy	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I hardly ever expect things to go my way	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I don't get upset too easily	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I rarely count on good things happening to me	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Overall, I expect more good things to happen to me than bad	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Please read through the items below and circle the number that represents your current situation.

	We have this	**We do not want/need this at the moment**	**We would like to have this but cannot afford it at the moment**
Laptops/Computers	0	1	2
Latest Mobile Smart Phones	0	1	2
Handheld Tablets (e.g. ipad, Kindle etc.)	0	1	2
The Latest Game Console	0	1	2
A Car/Van	0	1	2
Annual Family Holidays/Trips	0	1	2
A Night Out Once A Month	0	1	2
Buying New Clothes	0	1	2
Fresh Fruit and Vegetables Most Days	0	1	2
A Cooked Main Meal Everyday	0	1	2
Toys and Sports Gear For The Children	0	1	2

Background information about You & Your family member with Down syndrome (Referred to as *N* for name in the questions below)

Your **sex** is:
☐Male ☐Female

Your **Age Group** is:
☐Under 35 ☐35-49 ☐50- 64
☐65-79 ☐80+

You would define you Race, Ethnicity & **Nationality** as:
_____

Your Postcode is: _____

Your **Household Income** is:
☐Dependent on state benefits &/or pension
☐Less than £23,200
☐More than £23,200

Your **Occupation** is:
_____

Your highest **Level of Education** completed is:
☐Left school at 16 years or younger
☐A Levels/BTEC/Foundation etc.
☐Degree
☐Postgraduate☐ Other (please describe)
_____

Your **Relationship to *N*** is: ☐Mother
☐Father ☐Brother ☐Sister
☐Foster/adoptive parents ☐Other relative (Please describe)_____
Are you a lone carer? ☐Yes ☐No
Are you the main or joint-main carer? ☐Yes ☐No
How many children are there in your household? _____

Your family home's **Location** is:
☐Urban ☐Rural

Your **City/Town** is:
_____

Your **County** is:
_____

N's **sex** is:
☐Male ☐Female

N's **Age** Group is:
☐0-4 ☐5-9 ☐10-14
☐15-19☐20-34☐35-49
☐50-64☐65-79☐80+

N's **Home** is mainly (5 days or more):
☐With you
☐In a residential campus/centre, hospital or institution
☐In their own house in the community (including rented)
☐Other (please describe)_____

N's **Day activities** are: (tick all that apply)
☐Home based ☐Day/Training centre ☐Sheltered workshop
☐Regular employment ☐Supported employment
☐Mainstream School ☐Special School ☐College/University
☐ No day activities
☐ Other (write in)_____

***N's* Support Needs, Disabilities** and **Health needs** are:
☐None of the these
☐Intellectual disability ☐Difficulty speaking ☐Difficulty seeing ☐Epilepsy
☐Difficulty reading ☐Difficulty hearing ☐Attention problems ☐ Stubbornness
☐Mental Health problem ☐Physical disability ☐ Difficulty communicating ☐Autism
☐Other (write in)_____
Do you consider *N's* Intellectual disability to be
☐Borderline/Mild ☐Moderate ☐Severe/profound
Do you feel *N* can look after his/her personal care needs?:☐No ☐With help ☐Yes
Do you feel you can leave *N* unsupervised?: ☐No ☐For short periods ☐Yes
Can *N* travel independently by taxi, bus or train?: ☐No ☐Sometimes ☐Yes
Do you have difficulties around transport for *N*?: ☐No ☐Sometimes ☐Yes

***N's* Behaviour** that you may find challenging or difficult to manage:

Is *N* physically aggressive to you or others?:	☐No	☐Sometimes	☐Yes, a lot
Is *N* destructive to property or things?:	☐No	☐Sometimes	☐ Yes, a lot
Does *N* hurt him/herself on purpose?:	☐No	☐Sometimes	☐ Yes, a lot
Does *N* have temper tantrums or outbursts	☐No	☐Sometimes	☐ Yes, a lot
Is *N* withdrawn seeking isolation from others?	☐No	☐Sometimes	☐ Yes, a lot
Is *N* disobedient, difficult to control?	☐No	☐Sometimes	☐ Yes, a lot
Does *N* perform odd or bizarre behaviour?	☐No	☐Sometimes	☐ Yes, a lot
Is *N* listless, sluggish or inactive?	☐No	☐Sometimes	☐ Yes, a lot
Is *N* socially inappropriate in public?	☐No	☐Sometimes	☐ Yes, a lot
Does *N* perform odd or bizarre behaviour?	☐No	☐Sometimes	☐ Yes, a lot

Your Health

For each of the following questions please indicate the answer which best describes your response by circling the appropriate number.

Overall, how would you rate your health over the past 4 weeks?	Excellent	1	2	3	4	5	Very Poor
During the past 4 weeks, how much did physical health problems limit your usual physical activities (such as walking or climbing stairs)?	Not At All	1	2	3	4	5	Could Not Do Physical Activities
During the past 4 weeks, how much difficulty did you have doing your daily work, both at home and away from home, because of your physical health?	Not At All	1	2	3	4	5	Could Not Do Daily Work
How much bodily pain have you had during the past 4 weeks?	None	1	2	3	4	5	Very Severe
How much bodily pain have you had during the past 4 weeks?	Very Much	1	2	3	4	5	None
During the past 4 weeks, how much did your physical health or emotional problems limit your usual social activities with family or friends?	Not At All	1	2	3	4	5	Could Not Do Social Activities
During the past 4 weeks, how much have you been bothered by emotional problems (such as feeling anxious, depressed or irritable)?	Not At All	1	2	3	4	5	Extremely
During the past 4 weeks, how much did personal or emotional problems keep you from doing your usual work, school or other daily activities?	Not At All	1	2	3	4	5	Could Not Do Social Activities

Thank you for taking the time to complete this questionnaire.

We are also interested in interviewing some family members about their experiences, well-being and coping. If you are happy to be contacted by the researcher to take part in an interview to expand on some of the topics raised in this questionnaire please tick the box below.

I am happy to be contacted by the researcher for an interview ☐

My contact details are _____

Thank you for taking part in this study.

The aim of this study is to explore factors that affect the well-being of families who are caring for a child with Down syndrome. In addition this study is also looking at whether families experiencing greater hardship differ in terms of their wellbeing and the coping strategies they use.

The questionnaire you have completed will also be used to see if there is any association between the coping strategies people use and their feelings of well-being.

The information you have provided within the questionnaire will be kept confidential and anonymous and will be destroyed after a period of 2 years.

If you would like any further information on how your results will be used or you would like to withdraw please contact the researcher Jaspreet Uppal via EMAIL or the researcher's supervisor Dr. Darren Chadwick via EMAIL or NUMBER.

In addition, if you would like a summary of the results once the study is complete, please provide your contact details (postal address or email address) here. You will be sent a summary of the findings once the work is complete.

If you feel distressed or in need of further support, you can contact:

- Samaritans: 08457 90 90 90
- Mencap: 0808 808 1111
- Family Lives – 0808 808 2222
- Or you contact your GP for further advice on support available

Thank you again for your time and participation.

(Please detach this sheet and keep for your information.)

Appendix 4

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
FamilySupport	.064	93	.200*	.988	93	.558
SenseOfSupport	.124	93	.001	.969	93	.026
ConfrontiveCoping	.154	93	.000	.890	93	.000
Distancing	.125	93	.001	.967	93	.018
SelfControlling	.138	93	.000	.949	93	.001
SeekingSocialSupport	.079	93	.195	.987	93	.515
AcceptingResponsibility	.170	93	.000	.873	93	.000
EscapeAvoidance	.215	93	.000	.789	93	.000
PlanfulProbSolving	.131	93	.000	.961	93	.007
PositiveReappraisal	.149	93	.000	.931	93	.000
Resilience	.062	93	.200*	.983	93	.271
PhysicalHealth	.146	93	.000	.917	93	.000
MentalHealth	.195	93	.000	.866	93	.000
Extraversion	.105	93	.013	.956	93	.003
Agreeableness	.146	93	.000	.915	93	.000
Conscientiousness	.155	93	.000	.949	93	.001
EmotionalStability	.158	93	.000	.934	93	.000
OpenessToExp	.131	93	.000	.954	93	.002
Optimisim	.142	93	.000	.948	93	.001
Pessimism	.167	93	.000	.930	93	.000
OverallOptimism	.204	93	.000	.925	93	.000
DeprivationIndex	.189	93	.000	.914	93	.000
WellBeingOverall	.115	93	.004	.940	93	.000

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Appendix 5

Below is the email received by the researcher granting ethical approval for this research study.

Please find below the outcome from the BSEC meeting

Jaspreet Uppal (Dr Darren Chadwick & Dr Josephine Chen-Wilson)

Exploration of well-being of families from a low social economic background

Decision: Pass, Supervisor to monitor to ensure relevant changes are considered or made.

1. Seven q'aires seems like a lot. Is there any way of making this less burdensome for the participants? Are they all necessary? Jaspreet appears aware of this issue (p. 6). The fear must be that the quality of the data will be diminished if they run out of energy when doing all these, and this risks wasting their time in two ways; and also that they will be deterred from engaging in the first place (and low income is correlated with low educational attainment). Perhaps coping style (assessed by the longest instrument) could be left solely to the qualitative part of the investigation.

2. Bearing in mind the social/educational point: she could consider shorter and plainer info sheets and consent forms (common words, short sentences, all on one page).

3. Letter: don't use 'To whom it may concern' – address the recipient personally.